



Supporting older adults with a learning disability and their ageing family carers: A family and community support model (FULL REPORT)

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ACADEMIC REPORT

Supporting older adults with a learning disability and their ageing family carers: A family and community support model



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Literature review

Introduction

In this section, we explore the concept of 'ageing' in adults with a learning disability and attempt to provide an estimate of the size of the population. The majority of children and adults with a learning disability live with their families: likewise, for those older adults with a learning disability the majority also live with an ageing parent(s), mainly mothers or female siblings, many of whom are lone carers: this pattern will continue. We explore this family support model and the community supports provided by statutory learning disability services (i.e. building based day-centres, residential provision/supported living, respite/short breaks) to enable these ageing family carers to continue caring. We examine the concepts of '*ageing, retirement and transitions*' from the perceptions of the service user and family carers, and how services respond to these milestones in life's journey.

As adults with a learning disability age, they face many health and social care challenges, as do their ageing family carers. Similarly, statutory learning disability and/or mainstream older persons services are also challenged in how best to meet the health and social care needs of both the older person with a learning disability and their ageing family carers. We identify a number of policies, strategic and organisational directives that highlight that this traditional learning disability model will be less efficient and cost-effective in decades to come. Within the current financial climate, traditional service models will be unable to meet the future demands of the changing demographics of older adults with a learning disability and their ageing family carers. This section ends with the aims and objectives of the study, and a commentary on how these have been achieved.

Definition of a learning disability

Intelligence is assessed using a standardised intelligence quotient [IQ] test and individuals who have an IQ of <70 are identified as having a learning disability. The level and severity of learning disability is based on an assessment of IQ, level of social functioning and if the learning disability is acquired before the age of 18. Individuals who have a learning disability within the range of 50 to 69 are diagnosed

as having a mild learning disability. They can achieve full independence in self-care but may have delayed language acquisition and poor academic abilities. Individuals who have a learning disability within the range of 35 to 49 are diagnosed as having a moderate learning disability and have poor self-care, motor skills, limited language development and rarely achieve full independence. Individuals who have an IQ of <30 are diagnosed as having a profound learning disability, and are often severely restricted in mobility (BPS, 2007).

It is evident that the presence and level of learning disability may affect many aspects of an individual's life, including the ability to live independently, form relationships, and achieve academic and employability prospects. It is also apparent that having a learning disability may influence health outcomes, as individuals have a reduced capacity to understand and apply health promotion information to their lives. This makes them reliant on family carers, paid carers and support systems to enable them to exert self-determination in making healthy lifestyle choices.

Search strategy

A review of the literature was conducted using the Ovid, CINAHL and Psychinfo databases. The terms '*learning disability, intellectual disability, mental retardation and development disability*' were combined. In addition, terms for '*ageing, retirement and transitions*' were combined. Both these separate searches were then combined. A manual search was conducted of the reference lists and grey literature.

A Rapid Review of the literature on older adults with a learning disability and their ageing family carers was undertaken by Slevin, Taggart, McConkey et al. (2011) funded by the Public Health Agency Research & Development Office Division. This rapid review was undertaken using a framework adapted from the NHS Centre for Reviews and Dissemination (CRD, 2009) and the Rapid Review Methodology (NHS, Wales 2006). The main overarching question was what services and support do older people with a learning disability and their ageing family carers require to meet their needs? This review of the evidence compliments the current review further informing our evidence-base and leading to the aims and objectives of this project.

Prevalence of learning disability

It is estimated that approx.1%-2% of the world population has a learning disability: this figure varies pending definition, measurement, whether figures include those known to statutory services or not, etc. The Foundation for People with a Learning Disability (2010) estimated there to be approx. 1.5 million people in England to have a learning disability.

Based upon McConkey et al.'s (2003) report, it is estimated that there is a population of 26,500 people in Northern Ireland with a learning disability of whom half are aged between 0-19 years: this is based upon a prevalence rate of 1.5% of the population. However, when the numbers of people with a learning disability who are engaging in statutory services are collated across the five Health & Social Care Trusts and education department in Northern Ireland, this number decreases to approx. 16,366 (see Table 1).

Table 1: Prevalence of learning disability by age and severity in N Ireland

Age bands	Mild/moderate	Severe/profound	Total
0-19	6,432	1,718	8,150 (49.9%)
20-34	2,504	1,047	3,551 (21.7%)
35-49	1,489	949	2,438 (14.9%)
50 +	1,473	753	2,226 (13.6%)
Totals	11,898	4,468	16,366

(Table taken from the DHSSPSNI (2014): Statistics on People with a learning disability in Northern Ireland: Research and Information Service Briefing Paper (p. 3))

It is also worth noting that approx. 40% of people with a learning disability are not in regular contact with a statutory learning disability service provider in Northern Ireland: many of these people are more likely to have a borderline / mild disability and are functioning independently of statutory services with minimal support (McConkey et al., 2006; DHSSPSNI, 2014).

Estimation of future learning disability prevalence

According to NISRA (2015) in Northern Ireland the population aged 65yrs plus is projected to increase by 74.4% to 498,500 from mid-2014 to mid-2039, with the result that one in four people will be aged 65yrs plus. Similarly, the population aged 85yrs plus is projected to increase by 157.3% to 88,600 people over the same time period (a 1.9%-4.4% increase) (NISRA, 2015). As we clearly have an ageing population then the rates of ill-health, multiple chronic illnesses and disability will dramatically increase, thereby placing further strains on an already over-stretched health and social care sector.

It is difficult to give an accurate estimate of the future prevalence of learning disability as this will be based on a number of factors (e.g. growth of Northern Ireland population, childhood survival rates, diagnosis autism screening, mortality figures, etc.). Nevertheless, if we use the Northern Ireland 2001 and 2011 consensus data, and a 1.5% prevalence rate, according to the recent report by the RQIA (2016) it is therefore projected that the number of people with a learning disability will increase by 1% each year over the next 15 years (see Table 2). More so, adults with a severe/profound learning disability (presenting with complex health needs) will be a particularly large growth area.

Table 2: Estimation of learning disability prevalence based on census data

	2001	2011
Population	1,685,267	1,810,863
1%	16,853	18,109
1.5%	25,279	27,163
2%	33,705	36,217

Age profile of adults with a learning disability

An ageing population is a transnational demographic phenomenon with social, economic and political implications (WHO, 2016). Over the past century, the life expectancies for the general population have dramatically increased. Similarly, across many westernised countries life expectancies for people with a learning disability have also significantly increased (Braddock et al., 2001). Moreover, adults

with a learning disability age earlier compared to their non-disabled peers, with ageing commencing earlier at 50 years and for people with Down's syndrome 40 years (Bittles et al., 2002).

With regards to those older people with a learning disability known to statutory services in Northern Ireland, the number of adults with a learning disability currently aged 50 years plus accounts for 13.6%, with another 14.9% aged between 35-49yrs (see Table 1 above). These figures do not include those adults with a learning disability not known to statutory services, sometimes called the '*hidden invisible population*' (Emerson & Hatton, 2014), but may become known to services when there is a crisis (i.e. death of a family carer, physical health problems, mental health deterioration, needing hospitalisation and/or residential accommodation, etc.).

McConkey et al. (2006) stated that current prevalence rates of older people with a learning disability in Northern Ireland do not reflect the increased life expectancy of these persons. Emerson & Hatton (2004) have used mortality data from English Case registers to revise upwards prevalence rates for age groups of people with a learning disability over 50 years. Using their figures, the predicted population in Northern Ireland aged over 50 years in 2021 would be 35.7% (up from 26.8% in 2002). This means, statutory and voluntary learning disability and mainstream older person services must plan to ensure that this growing older population with a learning disability can be accommodated in age-appropriate day activities, residential accommodation, respite/short breaks and community programmes, thereby offering ageing parent(s) the support they need to continue to care but within the cost constraints of a modern health and social care service (Equal Lives, 2005; Compton Report, 2011; Northern Ireland Learning Disability Services Framework, 2012; RQIA, 2016). This study which was funded by Research & Development Division, Public Health Agency under the Bamford Research Programme will contribute to the evidence needed to realize this goal.

Health of older adults with a learning disability

Evidence demonstrates that people with a learning disability have a poorer health profile than the non-disabled population (WHO, 2011). In ascertaining the health disparities of people with a learning disability, it is therefore important to recognise

the interplay that the determinants of health have on this population: 1) genetic / biological factors; 2) individual lifestyle factors; 3) access to health promotion and healthcare; and 4) the socio-economic, cultural and environmental context) (Emerson & Hatton, 2014; Taggart & Cousins, 2014). Although the genetic / biological determinants of health cannot be directly targeted, the contributing factors to poor health of this population can be addressed (Marks & Sisrak, 2014).

With regards to individual lifestyle factors, there is clear evidence that individuals with a learning disability engage in high levels of sedentary behaviour, lower levels of physical activity, consume an unhealthy or high-energy diet and are prescribed high levels of psychotropic medication: consequently, leading to high rates of obesity (Phillips & Holland, 2011; Gephart & Loman, 2013). This is also a population who do not regularly engage in health promotion opportunities and access appropriate healthcare (Taggart & Cousins, 2014). These behaviours can put this population at risk later in life of serious health conditions such as coronary heart disease, certain cancers, Type 2 diabetes, etc. (Hu et al. 2005; Haveman et al. 2011; Taggart et al. 2014); and premature death (Heslop et al., 2013).

In the largest follow-up cohort study of older adults with a learning disability aged 40 years plus (N=843), McCarron et al. (2015) in Ireland reported that this population had an increased risk of obesity, osteoporosis, type 2 diabetes, mental health problems and dementia: with half of older adults with a learning disability having at least two chronic health conditions. Adults with severe/profound learning disability were more likely to experience respiratory, epilepsy and cardiovascular related health issues, and also cancer, at a younger age (Haveman et al., 2010).

Strydom et al. (2009) reported the prevalence of dementia in people with a learning disability to be 2-3 times more likely than in the general population. Rates of dementia in adults with Down syndrome are even higher and may develop when people are in their late 30's and 40's, and consequently may need additional care in their later years (WHO, 2000).

Ageing, retirement and transitions

The circumstances and expectations of people with a learning disability have evolved over more recent decades with a greater emphasis on inclusion and community living. While these are welcome developments which raise expectations for opportunities for positive ageing, there remain questions over how support for ageing generations is to be provided in the future.

In their systematic review of caring for older people with a learning disability, Innes et al. (2012) have argued that the ageing experience of these individuals with a learning disability should not be seen as exactly the same as those of the general population. While some of the biological processes of ageing are similar whether a person has a disability or not (except for specific associate conditions such as dementia and epilepsy), it is important to be aware of different life markers.

“People with an intellectual disability will have different experiences of childhood, education, relationships, employment and retirement. Generally, although not exclusively, people with an intellectual disability are not married, or parents, and have not been in paid employment. The debate will be explored between age related needs as distinct from the existing intellectual disability – a distinction that is not reflected in service provision or policy.”

(Innes et al., 2012, p. 286)

In a small qualitative study of perceptions of active ageing, Buys et al. (2008) noted that with the move away from institutional care, many older service users with a learning disability have had different experiences in the latter part of their lives that have led to new hopes and expectations on their part. Highlighted were themes of *‘being empowered, being actively included and involved in the community, maintaining skills and learning, having congenial living arrangements, having the best possible health and fitness, being safe and feeling safe and having satisfying relationships and support’*. However, while this research showed obvious parallels with what the general population would want for their transition into ageing, a key point was the considerable difference between what this group of service users currently experienced and what they would like.

For health and social care service providers, the expanded horizons which have come with the transition towards ageing and inclusion also brings a host of new challenges in terms of lifestyle support issues in order to assist new generations of older people with a learning disability move through this new '*unknown*' phase of their lives. Today's generation of older persons with a learning disability are the first for whom transitions are required to support movement from services provided to adult persons, towards provision that is more suited to their changing demographic and health needs.

Walsh et al. (2004) have also identified and recognised the needs of older women with a learning disability and how these should be supported by statutory services and community supports: and women as mothers. The authors concluded that the needs of older women with learning disabilities should be treated no differently than older women without a disability. Similarly, the needs of women with disabilities from different cultures also need to be recognised.

Policy, Strategic and Organisational Directives Promoting Family Support Models

The number of people with a learning disability living in hospitals and large institutions has been steadily declining with an international trend towards greater individualised supports and community inclusion. In the UK, Valuing People (Department of Health, 2001), acknowledged the poorer quality of life experienced by people with a learning disability living in hospital based settings and made a policy commitment to enable all people with a learning disability across the lifespan the opportunity to express greater choice and control about their living arrangements.

In their review of deinstitutionalisation across Europe, Mansell et al. (2007) found that while there was evidence to show higher quality outcomes for community-based models of care, there was no evidence that these community-based models were inherently more costly than institutions. Nevertheless, it was noted that the cost of supporting those with higher levels of need is higher than those who are more independent, wherever these individuals live. To facilitate the move towards community based residential provision, Mansell et al. (2007) recommended that the

development of national policy frameworks was a key factor and that these should be formulated within the context of International Instruments such as the 1948 Universal Declaration of Human Rights and more recently, the 2006 UN Convention on the Rights of Persons with Disabilities. In addition to the national commitment to deinstitutionalisation, local planning with appropriate consultation with all stakeholders was also advocated as a fundamental factor in the success of deinstitutionalisation initiatives and community integration.

Challenges to and support for the success of community living

There is more to deinstitutionalization than just hospital closure and merely moving people out of institutions into community settings as this does not automatically improve quality of life in terms of choice and inclusion (Beadle-Brown et al., 2007). A lack of appropriate supports within the local community can be a barrier to community integration. Changes to traditional family structures, large geographical distances between family members, the growing numbers of women working in full-time employment and the ageing profile of the general population, have all contributed to a reduction in the availability of informal family carers.

Over the last number of decades, the values and philosophy that have informed policy and practice for these family and community support have undergone a number of significant changes. These have included: the growth of the disability and human rights empowerment-based movement; the rights of the person with disabilities (UN, 2006); a number of caregiving theoretical models of stress and coping and family systems approaches (Pearlin et al., 1990; Grant et al., 2007); and the importance of obtaining the voice of the service user. The UN Convention on Rights of Persons with Disabilities' (2006) promotes the rights of all persons with disabilities to live in communities; freedom to make choices regarding their lives, including place of residence (access to a range of in-home, out-of-home (i.e. residential) and community supports) to prevent isolation/segregation from community. The UN Convention (2006) also stresses the need to prevent age-related disabilities and promote the social inclusion of older persons.

Family support model

Globally, families are the cornerstone of the provision of care for children with disabilities, with the majority of parents supporting their children in their own family home. This pattern of care is predicted to continue long into adulthood (Braddock et al., 2001), which will increase the demand for mainstream older person and learning disabilities statutory services, and services designed to specifically meet the needs of older people with a learning disability and their ageing family carers (Innes et al., 2012; Ryan et al., 2013). Supporting family carers has preventative benefits in terms of health and well-being, as well as in monetary gain, and is advocated in policy, strategic and organisational directives.

Numbers of older family carers in Northern Ireland

Within the UK, most people with a learning disability live with their ageing parent(s) or siblings (Foundation for People with Learning Disabilities, 2006). It is estimated that across the UK over 30,000 older parents (60 years plus) are caring for their son/daughter with a learning disability (aged over 40 years).

McConkey et al. (2006) in a comparative study between Northern Ireland and Ireland respectively, found more people with a learning disability lived with their parents, and most (64.8%) were aged between 40 – 64yrs with 32.7% of family carers aged 65yrs plus. More people with a learning disability in Northern Ireland were reported to have a severe/profound learning disability, to be more dependent and they had higher support needs compared to older people with a learning disability living with their ageing parents in Ireland. Lone carers were mainly women. McConkey concluded that these numbers will increase faster and provide families with added pressure to continue their caring role compared to Ireland and Great Britain.

Barron et al. (2006) undertook further detailed analysis of Northern Ireland and Ireland's learning disability databases. The demand for out of home placement was much greater in Northern Ireland, especially for lone carers. The authors concluded that family care arrangements into old age have received relatively little attention within government policy making, and hence service provision has been largely reactive. Internationally there is a call for future research into the changing needs of

older people with a learning disability and their ageing family carers and how they can be better supported (National Task Force, 2010).

Among the 16,366 people with a learning disability known to statutory services in Northern Ireland, most (almost 80%) live with family carers. With regards to ageing family carers (aged 60yrs plus) caring for an adult with a learning disability (aged over 40yrs), McConkey et al. (2003) indicated that approx. 1,200 people with a learning disability are residing with a family carer. Around 640 (53%) were single parents, mostly mothers. Despite this sizeable number of older family carers known to statutory services, there are also at least another 30% of these informal carers not known to services cross nationally: they only become recognised when care breaks down and a crisis arises (Janicki & Davidson, 1998; Thompson, 2002). This is a '*double-generation*' cohort of ageing family carers and adults with learning disabilities that are likely to continue to grow as more people are living longer (Hewitt et al., 2010).

Effects of caregiving on family carers

Research illustrates the long-term effects of caring for a relative with a disability: physical (i.e. arthritis, hypertension, poor mobility, obesity, increased diabetes and cholesterol), emotional (i.e. depression and anxiety), social (i.e. isolation) and being economically disadvantaged (Yamaki et al., 2009). Llewellyn et al. (2010) in a study of 64 family carers of adults with a learning disability in Australia found that better health was correlated with having an effective family support model (or informal support networks) (i.e. spouse/partner, siblings, extended family members, neighbours). Bigby (2002) stressed that a strong family support model was fundamental to a family carer's well-being. The availability of an effective family support model allowed many children and adults with a learning disability to remain within their home and also in their local communities. The benefits of these effective family support models for parent carers have been found to increase social support; lead to fewer feelings of loneliness and anxiety; less stress; and improved quality of life (Innes et al., 2012; Heller et al., 2016).

Krauss and Seltzer (1993) explained why these ageing parent carers wanted to continue to care for their son/daughter with a learning disability late into their lives: 1)

after many years of caring parents adjusted and accommodated to the caring role, and 2) parents build a long-term relationship with their son/daughter and do in fact gain and feel they have a purpose in their life fulfilling the caring role.

Future planning

Inevitably, there comes a time when other care arrangements are required. The health of the person with a learning disability, including their physical and mental health as well as chronic and enduring behaviours that challenge, may lead to family carers reluctantly exploring alternative care arrangements as they can no longer provide long-term care. More problematic are situations when family care ends through parental illness or death. The absence of adequate future plans and support systems can lead to crises and emotional trauma for all concerned (Bigby, 2004; Taggart et al., 2012), inappropriate placement (Thompson and Wright, 2001) and unexpected dilemmas for siblings or extended families (Ryan et al., 2013). Moreover, unplanned transitions are costly for service providers (Bigby and Ozanne, 2004). Additionally, some family carers may be unknown to services (Janicki et al., 1998) and may come forward only in times of desperate need.

Despite the rational arguments for proactively supporting ageing family carers to make future plans, available evidence suggests that this is not the case and that in many cases future planning is more aspirational than definitive (Bowey & McGlaughlin, 2007; Taggart et al., 2012). Various explanations have been proposed for these ageing parents' reluctance to relinquish their caregiving roles. Future planning is an emotive topic. Carers may not make plans as a result of denial about the inevitability of their own mortality and the realisation that they will not be able to provide care indefinitely. Moreover, they have difficulties in letting go of their loved ones as it may mean increased loneliness for them and an end to their role in life. Also, carers may harbour deep concerns and anxieties about what will happen to their relative in alternative out-of-home placements. They find the subject too painful to broach and do not make firm plans until it becomes unavoidable (McConkey et al., 2006; Bowey & McGlaughlin, 2007). Ageing family carers may lack information about new forms of care options and may be unaware of the long-time frames required to secure housing options and support outside of the home; reporting that there is 'plenty of time' (Ryan et al., 2013).

Siblings as future carers

Where parent caregivers are sometimes unable to provide care, siblings often take on the caregiving role. Heller and Arnold (2010) undertook an international literature review to examine the health of siblings of adults with a learning disability. Of 23 studies reviewed, the authors presented a mix of results but overall there was a positive picture of psycho-social outcomes being reported. Siblings, mainly sisters, reported maintaining long-lasting close relationships with their learning disability sibling and also anticipated taking on greater supportive roles as they grow older.

Managing changing reciprocities

Ageing family caregivers of people with a learning disability experience a number of unique challenges which will increase over time. In many families, the primary caregiver will be ageing and becoming increasingly frail with the result that they require additional care and support (Foundation for People with Learning Disabilities, 2003; Yamaki et al., 2009). Over the years, families develop routines and ways of coping with the result that both the ageing family caregiver and the person with learning disabilities look after each other. This is known as '*mutual caring*' or '*mutual support*'. The inter-dependency within these families, where the person with a learning disability adopts a caring role, is not uncommon and there is a growing awareness of the rise of '*mutual support*' (Grant, 1986; Walker & Walker, 1998).

The Foundation for People with Learning Disabilities (2010) concluded that an increasing number of adults with a learning disability in the UK are providing regular and substantial care for an ageing family member. This care ranged from help with personal care, dispensing medication, cooking and cleaning, to help with shopping and keeping the family member company as they go out. The report concluded that in many cases, neither the person with a learning disability nor their ageing family members would be able to remain living independently within their local community without this mutual support.

Mutual caring amongst ageing families often remains hidden. A report by Mencap (The Housing Timebomb, 2002), estimated that 29,000 people with a learning disability are living at home with family members aged 70 years or over. Moreover, the Department of Health report 'Valuing People' (2001) highlighted that one in four

of these families did not become known to statutory services until there was a crisis resulting in the potential breakdown of the caregiving arrangements. The Foundation for People with Learning Disabilities (2010) noted that there was no fixed point where the balance of caring tipped so that both the ageing family member and the adult with learning disabilities were caring for each other. Instead, this was usually a slow process where both parties gradually adapted to their changing role with the passage of time, unless in exceptional circumstances where the family member had an accident or suddenly became ill.

Service provision/community models

Service provision or community models for people with a learning disability have undergone significant changes over the past decades, with moves away from institutional to community-based models of care. These changes have been informed by a move away from a medical model to a social model of disability, with a focus on self-determination and the removal of barriers to equality of access to services, care and support (Barnes & Mercer, 2010).

Statutory Learning Disability Services

Slevin et al. (2011) undertook a Rapid Review of Learning Disability, Challenging Behaviour and Ageing funded by the, Research & Development Division Public Health Agency, Northern Ireland. This included sections on: *'ageing in place'*, *'facilitating and supporting ageing family carers through succession planning'*, *'how ageing family carers use formal services'* and *'the contribution of the older person care programme'*.

Many older adults with a learning disability will avail of statutory day services, this includes attending a day-centre and/or part-time education, and some may be involved in supported employment. However, this package of day services is based upon the person's level of disability and also where they live (McConkey, 2006). Some adults with a learning disability may also receive support from the community learning disability nurse, social worker, respite/short breaks and also domiciliary support for the person with a learning disability or their family carers. There are also a range of leisure activities for adults with a learning disability provided mainly by voluntary organisations such as Mencap, Positive Futures, Triable, Praxis, etc.

Despite the availability of this provision, the data in Northern Ireland raises concerns that compared to younger cohorts, older people with a learning disability received less day-care, less respite/short breaks, were less likely to have a social worker, received less domiciliary support and received less input from most health services (McConkey, 2006, McCarron et al., 2011, Slevin et al., 2011). Nevertheless, people prefer to remain with their families and this is the wish too of many family carers (Davies et al., 2002; McConkey et al., 2005; Taggart et al., 2012). Hence family support models need to be considered as part of the transition to old age for persons with a learning disability.

Mainstream older person services

There has been greater attention directed to family carer supports in terms of residential transitions as people with a learning disability age (McCallion & Kolomer, 2003), however few studies have examined the impact of people with a learning disability using older person day care models. The original models in the U.S. were proposed by Le Pore & Janicki (1997) and evaluated by Janicki & McCallion (1997). They found that the pooling of resources among learning disability specific and ageing services produced viable and effective programmes for both populations.

Collaborative working

Parish & Lutwick (2005) in the UK reported that there was limited consensus about whether services for older people with a learning disability (residential and day) should be integrated within mainstream older person services or learning disability services. When people with a learning disability reach old age, they are expected to integrate with older person's services, but issues arise as such services do not have the training and expertise to work with people with a learning disability. Service provision for older people with a learning disability across the UK is reported to be fragmented and piecemeal and it is not clear which agencies are responsible for service development. The authors stated that there were very limited opportunities for older people with a learning disability to express their views. Barriers included negative staff attitudes, the dominance of carer's views, lack of time, and the one size model fits all approach (Wilkinson et al., 2005). Factors that facilitate choice are knowledge of the service user's wishes, time to explore ways of communicating and

full assessment of changing needs and the need to use a family centred approach with older people with a learning disability.

Outcomes and costs of community models

There is a considerable if complex evidence base on the improved quality of life outcomes and cost efficiencies of models of community accommodation for adults with a learning disability compared with institutionalisation. Hatton & Emerson (1996) reviewed 118 papers that reported the comparative positive benefits and cost-effectiveness of residential and community models finding ample evidence of quality of life improvements in community settings but a need for more research on costs.

Within Northern Ireland, Beecham et al. (1997) examined the costs of re-settlement and found costs increased but also the quality of life for the person with a learning disability improved. However, the specific costs of day services in Northern Ireland have not been assessed for older persons with a learning disability in terms of present provision and no resource models have been developed to account for possible future costs of day and carer support provision arising from increased dependency.

Strydom et al. (2010) undertook an evaluation of the cost of services of 212 older adults with a learning disability (aged 60 years plus) in England. The majority of this sample resided in some form of a residential/supported living accommodation (83%), whereas only 17% of these adults with a learning disability resided with a family carer. The average weekly cost was £790 (£41,080) per older person with a learning disability in England. Overall costs were highest for those living in residential/supported living accommodation and lowest for those adults living with their families.

Northern Ireland Policies on Learning Disability Services

The *'Equal Lives Report'* (DSPSSNI, 2005) from the Bamford Review identified ageing as an area that required specific planning within learning disability services: *'the DHSSPSNI should produce a strategic plan to address current deficiencies in services and future service provision for older people with a learning disability and their families'* (Recommendation 52). To date, this recommendation has not been achieved.

The Compton Report (2011) recently reported that *‘the diversity and age appropriate nature of day services remains an issue for people with learning disabilities... ...a one size fits all service will be less attractive in the future’* (p. 95). Moreover, the Northern Ireland Learning Disability Service Framework (DSPSSNI, 2015) proposed that:

- All people with a learning disability aged 50 years and over should have the impact of ageing taken into account in having their future needs assessed and proactively managed
- People with a learning disability should be enabled to remain in their own home with their family carer for as long as possible with appropriate care and support to do so
- People with a learning disability have the same needs for autonomy, continuity of support, relationships and leisure as other older people and
- All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.

Bigby (2010) concluded that:

‘The intellectual disability service system will have to reorient to incorporate knowledge and expertise around age-related support needs ... and take responsibility for the development of specialist age-related services. It may also give the disability sector a much clearer mandate to lead and adequately resource partnerships with existing services [older persons care programme] or organizations (p. 11).’

Contextualisation: Ageing a new public health

Global trends indicate that by 2050 there will be 2 billion people aged over 60 years worldwide (WHO, 2016). According to Suzman et al. (2014) this ageing population *‘is poised to become the next global public health challenge’* as many people are developing a range of prolonged health co-morbidities (i.e. ischaemic heart disease, stroke, lower respiratory infections, chronic obstructive lung disease, diabetes and dementia) that place health services and public health under financial strain (WHO, 2016). Governments worldwide are being challenged to develop more age-

appropriate, evidence-based, efficient and cost-effective systems to meet this new public health threat. Likewise, within Northern Ireland, the Health Minister has set out an agenda to tackle the issues that face the health and social care sectors (including learning disability) (Health & Wellbeing 2026: Delivering Together, 2016).

Despite such frantic attempts by governments worldwide to meet this new public health threat for an ageing population, there has been few theoretically driven, robustly evaluated and coordinated models developed to support older adults with a learning disability and their ageing family carers to remain together within their family home. It can be purported that in many countries, including Northern Ireland, current service provision for these families is sparse, ad hoc and not based upon the needs of the older adult with a learning disability and/or the ageing family carer, but are service and financially driven (Bigby, 2008). Current models do not align to present-day self-determination and human rights principles that prevent age-related disabilities, promote the social inclusion of older persons and enable two generations to reside together (UN, 2006).

Older people with a learning disability

From the evidence presented above, people with a learning disability are living longer and also experiencing poorer physical and mental health compared to their non-disabled peers (Emerson & Hatton, 2014; Taggart & Cousins, 2014). As in many westernised countries, the majority of people with a learning disability in Northern Ireland also continue to live with their family carers. Although in Northern Ireland more adults with a learning disability live with their ageing family carers compared to other countries, and this pattern of care will continue giving the increase in prevalence of learning disability over the next 15-20 years (McConkey, 2006; DSPSSNI, 2015; RQIA Report, 2016).

As these adults with a learning disability grow older, they are continuing to live with an ageing family carer: many of these carers are mothers and lone carers. Some adults with a learning disability can live independently, while others move into a supported living scheme or a residential facility. Some families and people with a learning disability are offered respite / short-breaks but this is on an ad-hoc basis and varies on geographic location (RQIA Report, 2016). Day provision is offered by

both statutory and voluntary learning disability services, and comprises of a mixture of a traditional learning disability day-centre, day-opportunities (i.e. use of community social activities), education and supported employment. These day activities are offered to all adults with a learning disability regardless of age.

Retirement and transition

Compared to non-disabled adults where chronological age (normally 65 years), leaving from a job/career and receiving a company and/or state pension indicates '*retirement*', such significant events do not transpire for an older person with a learning disability (Innes et al., 2012; Ryan et al., 2013). The majority of adults with a learning disability are not in paid employment, there is no identified and agreed age for a person to '*retire*' (retiring from what to what), and older adults with a learning disability do not get a pension (they continue to receive benefits). In fact, many ageing family carers need the respite that traditional learning disability day centres provide so they can continue to care.

It therefore can be argued that the concept of '*retirement*' is alien to many adults with a learning disability, their family carers and also too to many statutory and voluntary learning disability service providers. Likewise, the concept of '*transition*' from adult to mainstream ageing services again is unfamiliar to many adults with a learning disability, their family carers and also too to many statutory and voluntary learning disability service providers.

Ageing family carers

Despite the ageing process and health challenges that these ageing family carers encounter, many have expressed the wish to continue to care for their son/daughter, and sometimes siblings, with a learning disability in their own family home. This has also been recounted by many older adults with a learning disability who also want to remain within their family home and with their ageing parent and/or sibling (McConkey et al., 2006; Taggart et al., 2012). Research has also clearly shown that these ageing parent carers and older adults with a learning disability are two vulnerable groups that are at risk, for a number of reasons:

- Many live-in poverty

- Many ageing family carers are more likely to be lone female carers
- Housing is often inadequate
- Health provision is neglected and
- There was a lack of coordinated formal support networks (WHO, 2000; Taggart et al., 2012).

Statutory service provision

Bigby (2003) reported that as adults with a learning disability age, informal support from family tends to decline as parents age and there is greater pressure required from health and social care services to provide a range of alternative support options. McConkey (2006) stressed that the demands for health and social care services for adults with a learning disability and their ageing family carers will rise, particularly as these '*double generation families*' are living longer. This has now been recognised by the Health Minister in Northern Ireland who has set up an Expert Advisory Panel on Adult Social Care and Support in 2016 within her document 'Health & Wellbeing 2026: Delivering Together'.

There is now a greater onus therefore to plan age-appropriate, evidence-based, efficient and cost-effective health and social care systems that support the changing needs of ageing family carers to continue caring for their son/daughter or sibling with a learning disability into the future. This is more urgent than ever in Northern Ireland given the projected growth in numbers of older persons with a learning disability in future decades, changing society structure, costs of current services and how people want greater choice and control over how care and support needs are met (DSPSSNI, 2015; RQIA, 2016).

Aims and objectives

Considering the literature presented above and the recommendations of the Research & Development Division Public Health Agency, Rapid Review that was commissioned on ageing in adults with a learning disability by Slevin et al. (2011), led to this specific question being advertised:

‘What service supports need to be put in place to ensure an effective transition from adult services to ones geared to meet the needs of older persons with a learning disability living with their ageing family carers? What are the costs associated with different options?’

There were three aims of the current study:

1. To examine how transitions within such services are best managed for ageing persons with a learning disability.
2. To provide an indication of the likely costs involved in providing services to older adults with a learning disability.
3. To document the most effective family support models and community supports (day activity, residential, respite/short breaks and community programmes) for older persons with a learning disability and their family carers.

To achieve these aims, there were five objectives:

- i. To examine what people with a learning disability would like to do in their ‘old age’ and the family carers’ aspirations for their relative with a learning disability
- ii. To explore what currently constitutes age-appropriate residential, day activity, respite/short breaks and community programmes within the learning disability and mainstream older persons services
- iii. To document the current use of day services and family support services by older persons with learning disabilities and their family carers, and their anticipated future need for services, including the transition arrangements in place
- iv. To examine the costs of residential, day activity, respite and domiciliary care within the learning disability and older persons’ programme of care and project likely future costs
- v. To reach a consensus across stakeholders as to what is considered to be optimal transitional arrangements and ‘best’ practice in service provision for older persons with learning disabilities living with family carers.

Commentary on aims and objectives

The two research questions and three aims of the study that have been achieved. Most of the objectives have been achieved except for the second part of objective 4, relating to projecting the likely future costs of services for older adults with a learning disability. There were difficulties in identifying and recruiting a representative sample of older adults with a learning disability and their ageing family or paid carers in Phase 3. It appears that family and paid carers did not want to share personal finance details and engage in a lengthy 1-1 structured interview (approx. 60-90mins) as carers reported they were very busy people. Meeting with family carer advocacy groups and speaking to families about their concerns regarding the information being collected in Phase 3, and offering a financial incentive, did help recruitment numbers although they did remain low. In addition, the recent RQIA Report (2016) in Northern Ireland highlighted the difficulties in obtaining accurate prevalence rates of learning disability across the five Health & Social Care Trusts as this information is not collated in a single regional common information system with agreed data sets. Therefore, we were unable to predict likely future costs.

Methods

Project Steering Group

The study had already identified a Research Project Steering group when developing the research proposal before submitting to the HSC, Research & Development Division Public Health Agency. All the Research Project Steering agreed to act as members of the project for the three-year duration of the project meeting 2-3 times per year and having involvement in each Phase of the project. This included identifying the aims and objectives of the study, methodology, obtaining ethical approval and research governance, identification of and recruitment of participants, receiving the results and findings of each Phase, developing and delivering the stakeholder event, and writing the policy brief document.

The group consistent of the following people including family carers: Professor Roy McConkey, Prof in Developmental Disabilities (UU); Agnes Luney, Chief Executive of Positive Futures; Dr Maria Truesdale-Kennedy (UU); Prof Assumpta Ryan, Chair of Ageing, UU; Dr Wendy Cousins, UU; Prof Mary McColgan, Prof of Social Work, UU; Mrs Paschal McKeown, Age NI; Mrs Margaret Campbell, Mencap; Mrs Moira Scanlon, Senior Occupational Therapist, SHSCT; Mrs Anne Murphy, Positive Futures; Mr Paul Roberts, Positive Futures; Mrs Isabel Kidd, Operational Manager of Day-Care, NHSCT; Mrs Rosaleen Harkin, Assistant of Director of Learning Disability Services, WHSCT and Mr Iolo Eillian, HSCB. We had three family carers who also sat on the Research Advisory Group: Mr James Higgins, Family Carer; Mrs Caroline Kelly, Family Carer and Mrs Sandra Harris, Family Carer.

Personal and Public Involvement

Although there were three family carers invited to sit on the steering group for the research project, their caring commitments and their distance from the University hindered their full participation in all group discussions. However tele-conferencing and email updates were used to increase their opportunity to contribute to the research outcomes for the project.

Design

The population under study involved adults with a learning disability in Northern Ireland aged 18 years plus and known to statutory learning disability agencies and living with family carers. This study involved four phases employing both qualitative and quantitative methods.

Phase 1 comprised a series of focus groups with younger and older people with a learning disability asking them how they would like to spend their day and leisure time; these focus groups sought the service users' preferences and aspirations. Alongside the service users' voices, their ageing family carers and other stakeholders also explored their thoughts on how such aspirations could be achieved. Phase 2 involved the use of a series of 1-1 structured interviews with senior managers from both learning disability and mainstream older persons programmes across Northern Ireland. Information was sought on current provision; their perceptions on what constitutes age appropriate day activities, respite and domiciliary care for older people with a learning disability.

Phase 3 involved a face-to-face survey with a sample of 97 adults with a learning disability living in Northern Ireland to examine their current service usage, costs and likely future needs/preferences. Phase 4 used a roundtable methodology bringing together a range of over 180 stakeholders in order to develop a community support model for older adults with a learning disability and their ageing family carers. The Model for Evidence-Informed Decision-Making in Public Health (The Canadian Institutes of Health Research, 2004) provided the framework for the roundtable discussions and the actionable outcomes that were to stem from these.

The sections below outline in detail the design of each of the four phases of the study and the findings/results found, this will be followed by an integrated discussion from all four phases and the recommendations stemming from this report.

Methods for Phases 1 & 2

Aim

A comparison of the views of adults with a learning disability, their family carers, and learning disability and mainstream older person's services on ageing, retirement and transitions

Objectives

- 1) To examine what people with a learning disability would like to do in their '*old age*' and the family carers' aspirations for their relative with a learning disability
- 2) To explore what currently constitutes age-appropriate day activity, residential, respite/short breaks and community programmes within the learning disability and mainstream older persons services

Design

Phases 1 and 2 of the study used a qualitative methodology employing twelve focus groups with the adults with a learning disability and five focus groups with their ageing family carers. In addition, six focus groups were also conducted with front-line staff within learning disability settings. In Phase 2 sixteen 1-1 interviews with senior service managers across learning disability services and the mainstream older person's services in Northern Ireland were also undertaken.

Participants

All participants were identified using a purposeful sampling strategy. A number of inclusion/exclusion criteria were developed. All staff that were recruited to participate in the focus groups had practical experience working with older adults with a learning disability in a day-care, residential accommodation and/or respite/short breaks.

Those staff that were recruited to participate in a one-to-one interview was either head of service/community service manager within either learning disability services or mainstream older person's services.

In total, 23 focus groups and sixteen 1-1 interviews were conducted with 165 participants, a combination of health and social care staff and managers; family carers and older and younger adults with a learning disability (N= 87) between October 2013 and September 2015. Thirty-four family carers participated in the six focus groups; 22 (64.7%) were female. A total of 87 adults with a learning disability participated in the focus groups across the five participating trusts. The group consisted of a sample of younger (under 30yrs) and older (over 50yrs) participants; 38 (43.7%) were female. There was a spread of participants from across the five trusts (SHSCT (26.5%), SEHSCT (24.1%), WHSCT (20.7%), NHSCT (18.4%) and Belfast (10.3%)).

With regards to staff the majority were female (87.8%); whilst the largest representation of staff (59%) was aged 46-55yrs old. The majority of staff were social workers (34.7%), managers (30.6%), community learning disability nurses (18.4%), occupational therapists (8.2%) and day-care workers (8.1%). There was a spread of participants from across the five trusts (SEHSCT (42.9%), SHSCT (26.5%), WHSCT (24.5%), Belfast (4.1%) and NHSCT (2%)).

In Phase 2 sixteen 1-1 interviews were conducted with Heads of Service; nine from learning disability services and seven from mainstream older person's services. The heads of service represented a range of community, day-care and domiciliary services. The majority were female (75%); whilst half of these staff (50%) were aged 46-55yrs old. There was a spread of participants from across the five trusts (SHSCT (31.3%), SEHSCT (25%), WHSCT (18.8%), Belfast (12.5%) and NHSCT (12.5%)).

Use of focus groups with adults with a learning disability

Informed consent was obtained from all adults with a learning disability with the use of a 'user-friendly' participant information sheet (PIS), that used pictures and simple language to fully explain the research study and each participant's role in the focus group interview. These PIS were distributed in advance of the focus group taking place and contact information for the research team meant that adults with a learning disability or their support staff could contact the team for more information, prior to consenting to participate.

On several occasions, a participant with severe speech difficulties had expressed an interest in contributing to the research, so with the permission of the other participants, a member of support staff also sat in on the focus group to facilitate the discussion. All focus groups, with the permission of the participants, were recorded and transcribed verbatim. A £10 voucher for Asda/Tesco was given to each participant with a learning disability and their ageing family carer who took part in a focus group. The voucher was a token of thanks from the research team to show our appreciation of their contribution to the research.

The role of people with a learning disability within research has changed significantly throughout the past thirty years. Historically adults with a learning disability have had research 'done to them', and were the subject to be studied, rather than the participant who is engaged with and included within the research process. Now researchers are much more aware of the benefits and rights of an individual with a learning disability to contribute to and have 'a say' in the research that they are involved with. Ethical concerns and recruitment remain the major barriers for including adults with a learning disability in focus group research (Gates & Waight, 2007).

In order to facilitate the groups and to ensure that all adults with a learning disability were comfortable and felt safe, the focus groups were arranged during the day whilst they attend their day activity or in the common area of their supported living accommodation. This ensured that all participants were along with a group that they knew and that they were in an environment that was familiar to them.

On a number of occasions, a participant with severe speech difficulties had expressed an interest in contributing to the research, so with the permission of the other participants, a member of support staff also sat in on the focus group to facilitate the discussion. All focus groups, with the permission of the participants, were recorded and transcribed verbatim, which afforded the research team the opportunity to focus on the detail of each member of the focus groups establish patterns across the different HSCTs.

Interview schedule

The semi-structured interview guide for the focus groups and one-to-one interviews were based upon the Rapid Review on Ageing in Learning Disabilities (Slevin et al., 2011). Many other key documents including WHO Framework of Active Ageing (WHO, 2002) and previous work by Bigby (2008, 2009) also guided the development of the interview schedules. Several broad topic areas were included in the interview guides including; understanding of the terms ageing and retirement and its applicability to the learning disability population; what constitutes age appropriate day activities for older people with and without a learning disability; transitions; the barriers and solutions to growing older with a learning disability and collaboration (if any) that exists between services. A question also explored what is required for older people who have dementia.

The family carer's interview schedule focused on ageing, transition and retirement and what if any currently hinders planning, as well as their thoughts on solutions to improve service provision in the future. The interview schedule for the adults with a learning disability was much simpler and several broad questions surrounding the concept of ageing, retirement and transitions were piloted with a group of older adults with a learning disability before the focus groups commenced. This pilot proved invaluable as it provided an opportunity to test the wording of the questions and prompts used to encourage participants to engage in the focus group process. All focus groups and one-to-one interviews were undertaken in trust facilities, during staff working hours and lasted approximately one hour.

Procedure

As per ethical procedures, a Local Collaborator was identified in each of the participating health and social care trusts. This local collaborator aided by research team member identified community learning disability team meetings and team leader meetings, which occur regularly within each trust, as suitable opportunities for focus groups to be carried out. Within each trust, the researcher conducted a focus group with community teams (included social workers and learning disability nurses) and team leader meetings (included managers from Day-Care, Residential / Supported Living facilities and Respite services). A focus group was also arranged with learning disability Occupational Therapists and Health Facilitators. All potential

participants received a Participant Information Sheet and Consent Form which they completed and brought with them on the day of the focus group.

Data analysis

To ensure the rigour of the data, all focus groups with staff, family carers and adults with a learning disability and 1-1 interviews with heads of service were audiotaped and transcribed verbatim (Slevin & Sines, 2000). The focus group and 1-1 interview transcripts were verified by a member of the research team and analysed separately utilising Newell and Burnard's Thematic Content Analysis framework (2012). The software package NVivo 13 was used to manage the data. The process of data analysis involved coding, reading and re-reading transcripts, developing categories, comparing, and grouping categories into meaningful themes and subthemes. Finally, the research team verified the themes and sub-themes from the focus groups and 1-1 interviews and a sample was returned to participants to ensure accuracy and consensus of the main findings (Slevin & Sines, 2000; Parahoo, 2014). Saturation was reached and agreed among the research team.

Ethics

The research team obtained ethical approvals from the Office of Research Ethics Committees Northern Ireland (ORECNI) and Research Governance Committee from each health and social care trust before the study commenced. In all trusts, a Local Collaborator was appointed to establish initial contact with trust facilities and identify appropriate services and individuals from Learning Disability Services and organize suitable dates and locations for the focus groups and 1-1 interviews. Informed consent was sought from all participants, who were provided with an appropriate information sheet detailing the study outline and their role, if they chose to participate. Confidentiality was assured as each participant was given a unique identification number, which was used during data analysis and subsequent write-up.

Findings for Phases 1 & 2

The themes identified in the focus groups and 1-1 interviews are presented below and are supported with evidence in the form of narrative accounts expressed by the adults with a learning disability, family carers, stakeholders and senior managers.

Theme 1: What does retirement mean?

Within this theme, there were three sub-themes: lack of understanding of retirement, retirement as a negative concept and a lack of planning for retirement/transition.

Sub-theme: Lack of understanding of retirement

There was agreement across the participants with a learning disability, their family carers and service providers that the concept of ‘retirement’ was ‘a meaningless term’. There was no clear age as to when retirement occurs and what would happen when the person with a learning disability does retire from their day activity.

‘There is no exit strategy from TRC’s (Training and Resource Centres), which is what they (adults with a learning disability) deem their work. We (non-disabled adults) expect to retire at a certain age but I don’t think our people (with a learning disability) in our day centres, I don’t think that they have any expectation around retirement’. (Staff FG 1)

Family carers highlighted that putting an age on retirement could be very difficult as the individual needs of those with a learning disability varied greatly from person to person. Participants with a learning disability also struggled with the concept of retirement and many expressed worry that retirement would force them to give up a part of their lives that they really enjoyed and looked forward to.

‘I think when you get older you get an awful lot more illness and you get dementia and you go doting, as they used to say in the olden days... it’s not nice, but it happens to us all’. (Person with a learning disability, FG 5)

Across the focus groups, older and younger adults with a learning disability (aged under 30yrs and over 50yrs) participated in focus groups. There were clear differences between the groups including how they viewed ageing; for younger service users it was easy for them to say, *'seventy or eighty'* was old and a good age to retire; however, those who were in their seventies still considered themselves young, and although some acknowledged a *'slowing down'*, most were not ready to retire.

Sub-theme: Retirement as a negative concept

For the participants with a learning disability and their ageing family carers many reported that this concept of retirement was perceived negatively about *'ill-health'* and *'no longer able to have a choice of engage in daily activities'*. Service providers however, acknowledged that there was a need for *'some sort of transition'* for older adults with a learning disability; however, they were very hesitant to say what the transition was that was required.

'I think the term retirement is misleading in some ways... family don't really, for want of a better word, push for planning for retirement. It is more... a transition'. (Staff FG 7)

The participants with a learning disability who contributed to the focus groups also viewed retirement largely negatively:

'When you retire, you have to quit the service (day centre) I think it is a wee bit unfair because some people mightn't want to quit and then they will have nowhere to go.' (Person with a learning disability FG 4)

However, a few adults with a learning disability did see retirement as something to look forward to and the opportunity to *'do something different'* and *'have more freedom and control over how they spent their days'*.

Sub-theme: A lack of planning for retirement/transition

There was agreement among both the family carers and the service providers that there was *'a lack of planning'* for how adults with a learning disability aged. The

statutory learning disability service providers worked hard to ensure that annual reviews and progress reports were up-to-date for all their clients with a learning disability across day care services and residential facilities. However, when asked specifically about planning for a transition or retirement in their client's future; they acknowledged that their service was largely *'reactive to the needs of clients and that financial concerns, waiting lists and demands for services meant that planning was restricted'* so as not to give clients false hope of what they may have access to in the future.

'With ours (clients with a learning disability) it is definitely reactive, it is reactive to something that has happened to them or they have become unwell or for some reason there is a change in the group and they don't really like it as much as they used to.... where someone starts to notice they are attending less, then we have a meeting about it, is there issues with transport or why are they not attending, and then they can say I don't want to or whatever the reason is. But we don't seem to have a plan in place for most of our clients'.
(Staff FG 4)

Family carers did not want to plan; a large proportion of those who contributed to the focus groups did not want to discuss a change or the need to change their son/daughter/sibling's caring arrangements when they get older. However, some were proactive about planning and wanted to do more to secure housing and support for their family members with a learning disability in the future. One older family carer (a lone father) strongly reported how frustrated he was with the system and the fact that they were not able to maintain plans as they progressed through different services.

'The very good example of that is when my daughter left school at nineteen years of age and she had all her care plans and I had my care plan every six months, it was great. Therefore, whatever her needs were, they had to be addressed or whatever, it worked really well. But the problem is all that paperwork, all that stays with the education system, they don't pass it over to the Trust and the Trust start with a blank canvas nearly so you have to then start that whole process again of saying this is my daughter, you know in a

statement. And they don't work together, and I don't understand why, and they won't do it'. (Family Carer, FG 5, Participant 1)

Theme 2: Service Participation

Within this theme, there were three sub-themes: limited or inadequate choice of services, the need for improved service opportunities and geographical inconsistencies across services.

Sub-theme: Limited or inadequate choice of services

There was agreement amongst all the focus group participants that services (especially living arrangements and choice of day activities/opportunities) could be better. Service providers acknowledged that staffing and financial constraints meant that they were not always able to offer clients with a learning disability the opportunity to do everything that they wanted. However, they stressed that a range of activities and opportunities were available across day centres and within clients' communities and that, every effort was made to ensure that clients were provided with appropriate day opportunities based on their assessed needs.

'We need an opportunity to talk about the complexities of moving them but also the joy of moving forward. Because there are some people (with a learning disability) that reach a certain age and they do want to live more independently'. (Staff FG 2)

Families reported their frustrations at the lack of choice and availability of day opportunities within their communities. They did acknowledge the good work of day care workers and relied upon their family member with a learning disability enjoying their day activities, however they noted that more choice as their family member aged, and flexibility of evening and some weekend activities would greatly enhance their quality of life as a carer and provide a more relevant service for their family members with a learning disability.

Sub-theme: Need for improved service opportunities

Across all focus groups, there was clear agreement that statutory learning disability services could be improved, and better opportunities could be offered to those with a

learning disability who are ageing. While statutory service providers acknowledged that improved service opportunities were needed, they acknowledged the difficulties currently faced across learning disability services in Northern Ireland.

‘...If we are talking about developing services, we have to do it within the remit of what money is available at this minute and time. And should it be that we co-ordinate all elderly services under one umbrella, irrespective of what their disability is, but then you have to be sure that these people know how to meet the needs.... but if you put them into a generic service where people don’t have that amount of training, you would be a bit concerned about how these people are treated and how their needs are being met’. (Staff FG 3)

Sub-theme: Geographical inconsistencies across services

Families also outlined the differences in service provision such as short breaks / respite; depending on the Trust area that you lived in. They stated that these differences were unfair and were putting their family member with a learning disability at a disadvantage.

‘I think it’s unfair that the different Trusts have such differences in the respite they are able to offer. Ours is very regimented ... But they (Trust) have not increased their bed capacity in the past fifteen years’. (Family Carer, FG 5, Pt 4)

The statutory learning disability service providers from across the five participating HSCTs also noted the differences in service provision, although they highlighted that services were catered towards the community that they served and tailored to meet the needs of the population of adults with a learning disability that utilised them, there were gaps in service provision especially in more rural areas.

‘Because we have very few people (staff), I had one lady who lived out in a rural area and the neighbourhood looked after her as much as we did and we went in as often as we could. But if it wasn’t for the neighbours or the people involved she couldn’t have stayed at home as long as she did’. (Staff FG 9)

Theme 3: The Same, but Different

Within this theme, there were three sub-themes: family-centred versus person-centred; the role of generation on caring and equality issues.

Sub-theme: Family-centred vs. person-centred

All of the participants across the focus groups spoke of the individual needs every adult with a learning disability has and how these vary immensely from person to person. Some of the participants' comments indicated a friction between meeting the needs of the adult with a learning disability and supporting the family unit.

'I don't care who says it, it is the parents who know what their son or daughter is capable of. We are living with them twenty-four hours a day, seven days a week; we know what they are capable of. We should be able to decide and plan for it'. (Family Carer, FG 4, Pt 4)

A number of the adults with a learning disability who contributed to the focus groups spoke about occasions when they wouldn't have a say about the activity or accommodation that they attended, that the *'choice was made for them'*.

'Sometimes my mummy and daddy say you can't do that or that trip (overnight group camping trip) isn't for you, but I want to try...the pictures look like fun... I didn't get to go with them'. (Person with a learning disability, FG 1)

Senior managers across learning disability and mainstream older people's programme of care also recognised the difficulties in meeting the needs of older people and their carers at a time of scarce resources.

'But it can be difficult because very often family and the person themselves may have an expectation that unfortunately we are just not able to meet'. (Senior manager, Mainstream Older Person Services, Interview 3)

Sub-theme: Role of Generation on Caring

There were differences in how the family carers viewed the services provided by the statutory learning disability service; some older family carers were very frustrated

with a lack of choice of services and limitations in respite/short break opportunities. Younger family carers welcomed the different choices in education and day opportunities (i.e. greater use of local community activities) for young family members with a learning disability but this varied upon geographic location.

Statutory service providers too noted the differences and changes in the role of their service in supporting adults with a learning disability and their families as they age.

'Families say they are copying, when you know they are not... it can restrict the person with the learning disability, like older family carers, some are unable to drive at night, (pick up from late social activities); for other ones (clients with a learning disability) then it involves their ability to care for somebody because they are actually taking on more of a responsibility looking after their elderly parents so there can be a whole complex series of things going on'. (Staff FG 9)

Sub-theme: Equality issues

Across the focus groups with statutory learning disability services and family carers spoke about inequality and their views on the social status of an adult with a learning disability. One staff member stated:

'The big issue here is actually to try and look at not just resources, but the social status of people with a learning disability. They really do not have any social status within our communities and I think that should be a huge priority of government to actually start looking at. This group of extremely vulnerable people deserve far better, should be higher up the pecking order... Resources are fantastic if we get them, but actually if the attitudinal barriers are broken down, our lives would be so much easier in terms of facilitating people. People with a learning disability are bottom of the pile and it does not matter how many strap lines or how many policies you have in place about capacity, consent, informed consent. You know we have talked today about how often it is about the carer's needs rather than the person with the learning disability, for very good reasons. You know inter-dependant relationships are what make it work'. (Staff FG 4)

Theme 4: Awareness and Collaboration

Within this theme, there were three sub-themes: the need for more responsibility and awareness generally; need better community engagement to alleviate stigma and more collaboration between services.

Sub-theme: More responsibility and awareness

Amongst statutory learning disability services and family carers there was agreement that the needs of adults with a learning disability were largely '*misunderstood*' and that those in the community providing public services did not always make the '*reasonable adjustments*' necessary to allow an adult with a learning disability to be inclusively involved within their activities/services.

'Offering places in a leisure centre is not enough, who is going to support that person with a learning disability to access that service, we (learning disability staff) can't do everything. Staffing will not allow it'. (Staff, FG 2)

There was agreement that more education and awareness of learning disability and the support needs of someone with a learning disability would help build knowledge and allow those with disabilities to engage better with their local communities.

Sub-theme: Better service/community engagement to alleviate stigma

Family carers and adults with a learning disability also welcomed the idea of being able to participate more in local community activities. Participants with a learning disability wanted to belong to their communities and do the same activities as everyone else. However, family carers were more cautious and worried about how '*vulnerable*' being in the community would make their son/daughter with a learning disability. Although one family carer acknowledged that her son attended a bowls club with her weekly and that, the entire group had '*made him very welcome*' and really engaged him within the group.

'I think what has been said, retirement doesn't really mean anything, certainly in terms of our son who is 51 years of age. As he gets older of course, we have noticed changes in routine, but routine is very important... It just cannot be that he comes home and stays there, he has to get out and mix with the

community and be part of that. I worry about how that is going to happen after we are gone'. (Family FG 4, Pt 2)

Sub-theme: Lack of collaboration between services

Across the focus groups, all participants noted that there was a lack of collaboration and at times communication between services. Examples included between day and residential services within statutory learning disability services; between statutory and voluntary learning disability services; and between statutory learning disability and older person services, and primary and secondary healthcare. This lack of communication left many family carers '*very frustrated*' as it culminated in instances when forms would have to be completed on '*numerous occasions*' and '*the same questions being asked*' by several healthcare professionals.

For staff, especially those in day-centres and in residential accommodation, the lack of co-operation between services put '*additional stresses*' on their staffing levels as for example a staff member would have to accompany a person for a hospital visit as the hospital had '*no one with learning disability experience on duty*' to support the person at their appointment. Staff also recognised that a more collaborative approach would also require a different way of allocating resources.

'We need to rejig resource allocation. We need to divert more resources from acute to primary care. We need to look at possibly, I feel, clawing back some of the resources we are putting into private providers and maybe increase our domiciliary care services.' (Senior Manager, Mainstream Older Person's services, Interview 1)

The participants with a learning disability also commented on this and that they had spoken on occasions when they were '*unable to go*' somewhere or attend an activity because no one was able to accompany them.

Theme 5: Looking to the Future

Within this theme, there were three sub-themes: a fear and reluctance to change; the important role of statutory learning disability staff; and the need for inclusive planning moving forward.

Sub-theme: Fear and reluctance to change

Across the focus groups, there was a consensus from all participants that change was not a positive concept; whether that is a change in service or day activity, a change of routine or staff, or a change in the form of retirement. Statutory learning disability service staff commented on their *'lack of freedom'* to change; their organisation/trust was such that it had a way of operating that was *'beyond their control'* to change. Family carers were very open about their *'fears regarding change'*. Many spoke of the *'turmoil'* and *'upheaval'* that they had experienced when their relative with a learning disability transitioned from child to adult learning disability services and they were not willing to go through another change of service.

The participants with a learning disability also expressed concern and fear over having to change their day activity or *'not be able to see friends'*. They also spoke about their fear of having to leave their home; whether that was the family home because mum or dad were no longer able to take care of them, or supported living scheme because their personal/nursing needs had increased, and the accommodation was no longer able to provide them with the support that they required.

Learning disability service managers also recognised the challenges associated with changing the status quo and the implications this would have for policy and practice.

'Traditionally learning disability services have been provided from birth to death and that is the traditional line of thought. It would require quite a significant change in the whole commissioning process through local collaboration to change that'. (Senior Manager, Learning Disability Services, Interview 3)

Sub-theme: Important role of learning disability staff

Amongst all of the participants, there was a lot of praise for the good work being done on the frontline by both the statutory and voluntary learning disability staff. Service providers and family carers commented on the *'time and effort'* that staff put in and their *'knowledge and expertise'* in caring for and looking after the adults with a learning disability within their services/centres. The adults with a learning disability

also commented on how staff were their *'friends'* and how well they knew and understood them and their needs. Learning disability staff also recognised the changing needs of their clients because of the ageing process.

'We have tried to incorporate a more person-centred assessment and care plan approach. We are trying to take into account the needs of the person and their views in terms of what they want for the future.' (Senior Manager, Learning Disability Services, Interview 2).

The knowledge and expertise of front-line learning disability staff is invaluable and was noted again with regard to the complex health issues of those with a range of learning disabilities as they age. Service providers and family carers noted that they were experiencing more and more health concerns with regard to the older adults with a learning disability in their care. However, whether it was a physical health issue (such as diabetes, cancer, heart disease, frailty issues) or a mental health issue (anxiety, depression, challenging behaviour, dementia), specialist health and social care staff from specific departments were able to cope with the person's needs, and these staff were invaluable in advocating on client's behalf and noticing changes that were not related to the person's learning disability.

Sub-theme: Need for inclusive planning

Across all the focus groups, it was clear that all participants wanted to be able to plan for the future. Planning included all aspects of the person with a learning disability's life including living arrangements, day activities, social interactions and family time. Planning is being hampered though by the current strains on statutory learning disability services and other health and social care services. Financial constraints are also hindering planning and in many instances dictating the services that are or are not being offered. It was clear from talking to statutory and voluntary learning disability service providers and also family carers, that each aspect of a person with a learning disability's day/life had an impact on the others. For example, one staff member stated that an older person with a learning disability in their day-centre could do with fewer and shorter days; however, this would have a *'knock-on effect on their supported living arrangement'* as staff were not currently there during the day. Day activities were acting as a form of *'day-care'* and as such, many

families were relying on day care for '*respite*', so that siblings/parents could rest or work. Others acknowledged the role of the voluntary sector and community groups.

'I think we can be working more closely with community groups such as churches, such as bowling clubs, such as bingo centres, that sort of thing where you are going to get older people there'. (Senior manager, Older People's services, Interview 2)

The adults with a learning disability viewed their day activity as a vital social interaction and for many living with older family carers, it was their only opportunity to get out and meet people. Planning therefore was described as a very delicate balancing act to ensure that the needs of the adult with a learning disability continue to be met, as well as the support required by family carers to enable them to maintain their caring role.

Methods for Phase 3

Aim

A comparison of the health and social care service utilization and costs for adults with a learning disability in Northern Ireland

Design

A face-to-face survey was undertaken with a sample of 97 adults with a learning disability living in Northern Ireland to investigate health and social care service utilization and costs (including drug usage) compared with: where you live (residential accommodation versus family home), age (18 – 30 years versus 50 years plus), gender and health (physical and mental health conditions).

Participants and consent

Recruitment occurred between Feb'15 - April'16 and a range of a priori methods was used to identify potential participants. We recruited from both learning disability statutory and voluntary services across Northern Ireland (community teams, day centres and residential providers). The eligibility criteria were: 1) participants were between 18 - 30yrs or 50yrs plus, 2) had a diagnosed learning disability, 3) living in the community (i.e. residential facility, 24 hr staffed group home or nursing home) or within the family home, 4) have the support of a family or paid carer. The definition of a family or a paid carer was someone who is either a family relative or residential member of staff who engages in the support of the person with a learning disability.

Demographic questionnaire

A demographic questionnaire was developed by the research team to collect information on age, gender, level of learning disability (see below), accommodation, marital status and ethnicity: and completed by the person with a learning disability and their family/paid carer together if possible. In addition, questions were asked about the participants' physical and mental health conditions, and whether challenging behaviours were displayed. We did not ask whether the person with a learning disability had an autistic-spectrum disorder.

Level of learning disability

The Ability and Development Criteria questionnaire was utilised as a short five-item scale completed by the family/paid carers to assess the persons' level of learning disability (i.e. mild, moderate, and severe/profound). The level of learning disability is calculated by totalling the scores of the five items and then referring to levels set for each range (Mild= score of between 5–8; Moderate= score of between 9–13; Severe= score of between 14–19; Profound= score of between 20-25). The Ability and Development Criteria scale has been used previously to assess the level of learning disability in other health related research studies including obesity and physical activity intervention research (Melville et al., 2007).

Residential, day activity, primary healthcare, secondary healthcare and drug utilization and costs

Residential accommodation (i.e. supported living scheme, 24 hr staff group home, nursing home, etc.), day activity (i.e. attending a day centre/day opportunities, etc.), primary healthcare (i.e. community healthcare services), secondary healthcare (i.e. hospital care) and medications were collected using the Client Service Receipt Inventory adapted for people with a learning disability (Beecham et al., 2001). Costs were dealt with by multiplying activity by unit costs.

Residential accommodation included those adults with a learning disability residing in a supported living scheme, a residential accommodation (24 hour staffed, group home) and a nursing home. These three facilities were grouped together for ease and known as 'residential accommodation'. The costs of these three types of residential accommodation were based upon the national costs for similar accommodation reported in the PSSRU (2014), and where these costs were not available obtained through personal correspondence with the Health & Social Care Board (HSCB), Northern Ireland.

For example, the costs for those adults with a learning disability residing in a supported living scheme were estimated to be approximately £39,000 per annum (personal communication). Average costs for those with a learning disability residing in a residential accommodation/24 hr staff group home were estimated at £53,000 per annum and for those residing in a nursing home £62,660 per annum (pages 71-

72, PSSRU, 2014; personal communication with HSCB). We acknowledge there can be variation in such costs depending on the individual package of care.

Day activity included whether the participant with a learning disability attended any of the following: day-centre/day opportunities, college of further education, supported employment and/or recreational activities: and whether these activities were provided by statutory or voluntary organisations in the past week on a Monday – Friday basis. Again, costs for day activity/day opportunities were obtained from the PSSRU (2014) for statutory day-care: this was estimated to be £57 per day. However, costs for day-care/day opportunities provided by voluntary organisations were based on an average of several organisations estimates: approximately £33 per day. We acknowledge there can be variation in such costs depending the individual package of care.

Primary or community healthcare services included attending or receiving any of the following in the previous 12 months: GP, dentist, optician, social worker, practice nurse, home help, physiotherapist, speech and language therapist, occupational therapist, psychiatrist, psychologist, community learning disability nurse and community psychiatric nurse. Secondary or hospital healthcare included whether the participant attended any of the following in the last 12-months: out-patient appointments, Accident & Emergency Dept. and admissions to hospital for any period of time.

Service use was monetised using standard references including PSSRU and Department of Health Reference Costs (2014). Byford et al. (2007) found that information collated by the CRSI and GP records have been relatively fairly good.

Drug costs were estimated cognisant of dose, frequency of use and the name of the medicine prescribed; these were monetised using the BNF. Monthly drug costs were subsequently converted to an annual figure by simply multiplying by 12. It is possible that this may have resulted in an overestimate of some drug costs taken for acute episodes of illness, for example, in relation to analgesics. Given the random nature of such illnesses, it is likely that over all individuals and in sub-group analyses, for

example related to gender, the estimated average cost in respect of such drugs reflects the actual average over the course of the year.

Statistical analysis

Descriptive statistics for the entire sample in terms of each element of cost, as well as aggregate healthcare costs were estimated. Bivariate analyses based on the difference in means costs (in total and by component) between groups differentiated by age, gender and living circumstances (those who lived with family and those who resided in a residential accommodation or supported living scheme) were undertaken. We are assuming that older adults with a learning disability would be using more traditional forms of day-centre whereas younger adults with a learning disability would be engaging in a variety of activities such as education, supported employment and in local communities alongside day-centre activity.

Relationships between costs (in total and by component) and age, as well as the number of physical and mental health conditions experienced by the participant with a learning disability were examined using pairwise correlations. Relationships between the number of physical and mental conditions reported and costs were examined rather than relationships between costs and specific conditions. Up to eighteen physical conditions and six mental health conditions were recorded in the survey, many individual conditions being experienced by relatively few clients. Given this and the sample size (just 92 usable observations), a count of conditions (one for physical health one for mental health), offered a more pragmatic approach to examining the relationship between morbidity and service use rather than examining variations related to specific conditions.

Multivariate regression analyses were used to examine the relationships between each component of cost and all costs combined. Age, gender, the number of physical and mental health conditions experienced and living circumstances were used as covariates. A sktest was used to examine the normality of each component of cost and all healthcare costs aggregated. In each case the data was found to be skewed.

Given this, a common feature of healthcare cost data; the models were estimated using a generalised linear model (GLM) with a log-link function and a Gamma distribution for the mean-variance relationship for each component of cost. A linktest and Park Test were used to examine the appropriateness of the structural equation and the appropriate distributional family for the link function. Cost functions were estimated with robust standard errors. In the case of aggregate healthcare costs (the sum of the various components), a GLM model with a log-link function and a Poisson distribution for mean-variance relationship was used following the outcome of the Park test and link tests. In the case of each regression marginal effects are reported to assist interpretation.

Ethics

The Office for Research Ethics Northern Ireland (ORECNI) approved this study and research governance was obtained across the five health service trusts. Verbal and/or written consent was sought from both the adults with learning disabilities and from their family/paid carers before they entered the study.

Results for Phase 3

Demographic details

Table 3 shows the participants demographic details. We were able to recruit 97 adults with a learning disability into this stage of the study, 76% were over the age of 50 years plus and 24% were aged between 18-30 years (average age= 48.7yrs). Half were female, and half were male, however more females were residing in residential accommodation (61%) compared to more males residing with their families (59%). Less than a half of the participants resided in residential accommodation (N= 41 (42.2%)) and 56 adults resided with their families (57.8%).

Level of learning disability

Using the Ability and Development Criterion questionnaire, just over half of the adults with a learning disability were reported to have a severe/profound disability by their family or paid carers (55%), 39% were reported to have a moderate learning disability and 6% were reported to have a mild learning disability. Using a chi square test, a significant difference was found in that most adults with a severe/profound learning disability resided with their families (70%) compared to 30% residing within residential accommodation (chi sq= 15.1, $p < 0.001$). Whereas, the majority of adults with a moderate learning disability resided in residential accommodation (59%) compared to 25% who resided with families. Only a small number of adults were reported to have a mild learning disability who resided with their families (4%) and in residential accommodation (10%). No significant differences were found between level of learning disability, and age and gender.

Physical health conditions

Table 3 shows the participants physical health conditions. The most common physical health conditions were sensory problems (51%), chronic constipation (36%), epilepsy (33%), reflux/swallowing difficulties (29%), digestive problems (16%), arthritis (16%), hypertension (12%), diabetes (11%), circulatory problems (12%), respiratory problems (9%), asthma (7%), cardiovascular problems (6%), osteoporosis (4%) and cancers (2%). The average number of physical health conditions was for males was 2.75 (std deviation = 1.15) (range 0 - 7) and for

females was 3.08 (std deviation = 2) (range 0 - 9), indicating females had more physical health conditions but these were not statistically significant.

Table 3: Demographic details of the participants

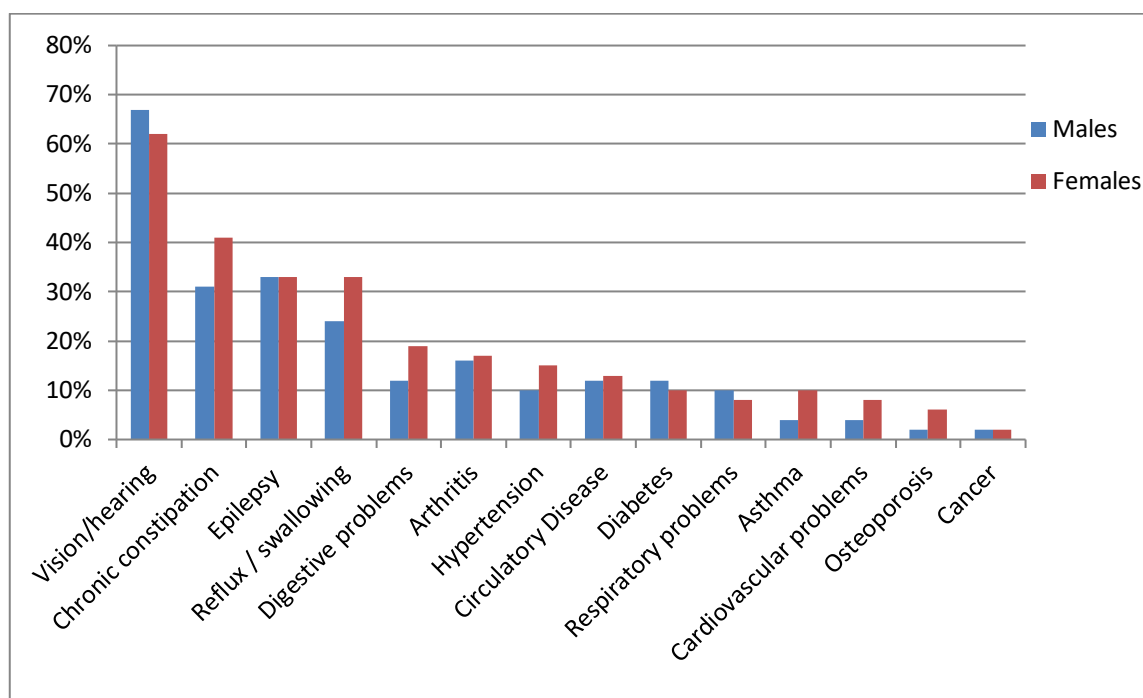
	Family (N= 56)	Residential (N= 41)	Total (N= 97)
Age (mean= 48.7yrs)			
18-30 years	34%	10%	24%
50 yrs plus	66%	90%	76%
Gender			
Male	59%	41%	50%
Female	41%	61%	50%
Level of learning disability			
Mild	4%	10%	6%
Moderate	25%	59%	39%
Severe/Profound	70%	30%*	55%
Physical health			
Vision/hearing	55%	44%	51%
Chronic constipation	29%	46%	36%
Epilepsy	39%	24%	33%
Reflux / swallowing	32%	24%	29%
Digestive problems	11%	22%	16%
Arthritis	16%	17%	16%
Hypertension	13%	12%	12%
Circulatory Disease	11%	15%	12%
Diabetes	5%	20%**	11%
Respiratory problems	11%	7%	9%
Asthma	7%	7%	7%
Cardiovascular problems	7%	7%	6%
Osteoporosis	4%	5%	4%
Cancer	2%	2%	2%
Mental health			
Displays challenging behaviours	39%	46%	42%
Anxiety	38%	39%	38%
Depression	14%	39%***	25%
Dementia	5%	7%	6%
Schizophrenia	0%	5%	2%

*(chi sq = 15.1, p<0.001), **(t= 2.204, p< 0.05), ***(t= 2.204, p< 0.05)

There were no significant differences found between most of these physical health conditions in terms of where the person resided. However, there was a significant difference found for diabetes between those residing within residential accommodation (20%) and those residing with their families (5%) ($t = -2.204$, $p < 0.05$) (see Table 1).

Using a series of Independent T tests, there were statistically significant differences found for those aged between 18 - 30 years compared to those aged 50 years plus on the physical health conditions: diabetes (0 versus 0.15: $t = -1.97$, $p < 0.05$), arthritis (0 versus 0.22: $t = -2.249$, $p < 0.05$) and sensory problems (0.3 versus 0.57: $t = -2.24$, $p < 0.05$). This may have been expected given that these physical health conditions are more associated with the ageing process, and more of the older participants with a learning disability were residing within residential accommodation.

Figure 1: Physical health conditions for male and female participants (N= 97)

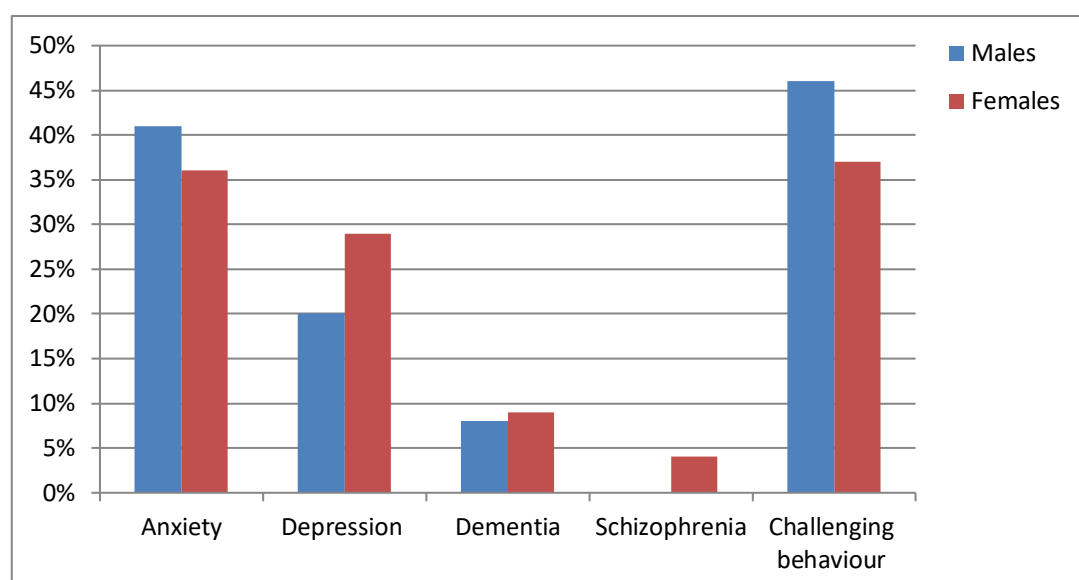


There were no statistically significant differences found between these physical health conditions and gender. However, Figure 1 illustrates that females were more likely to experience more physical health conditions compared to males specifically chronic constipation, reflux/swallowing problems, digestive problems, hypertension, asthma, cardiovascular problem and osteoporosis.

Mental health conditions and challenging behaviour

Table 3 above also shows the participants mental health conditions. The most common mental health condition was anxiety (38%) followed by depression (25%), dementia (6%) and schizophrenia (2%). The average number of mental health conditions was 1 (range 0 - 2). There were no significant differences found between most of these mental health conditions in terms of where the person resided. However, there was a significant difference found between those residing in residential accommodation (39%) and those residing with families (14%) for depression ($t = -2.204$, $p < 0.05$) only.

Figure 2: Mental health conditions for male and female participants (N= 97)



There were no statistically significant differences found between the other mental health conditions and gender. The average number of mental health conditions for males was 0.67 (std deviation = 0.8) (range 0 - 2) and for females was 0.75 (std deviation = 0.9) (range 0 - 3), indicating females had more mental health conditions but these were not statistically significant. Figure 2 illustrates that females were more likely to experience more mental health conditions compared to males specifically depression and schizophrenia.

In terms of challenging behaviour, 42% of participants were reported to display a range of disruptive behaviours as reported by the family/paid carers. There were no

statistically significant differences found between challenging behaviour and where the participant resided, age and gender although males were reported to display challenging behaviour more than females (see Figure 2).

Medications

Most participants with a learning disability were on at least one medication (90.7%) for their physical and/or mental health conditions (range 0 - 18 medications). The average number of medications reported for this sample was 4.5 (median= 3). Using a series of Independent T Tests, it was found that those participants who resided in residential accommodation were prescribed more medications (mean= 6.43) compared to those participants who resided with their families (mean= 3) ($t = -4.4$, $p < 0.001$). Females were statistically more likely to be prescribed more medications (mean= 5.6) compared to the males (mean= 3.4) ($t = -2.87$, $p < 0.001$) and those participants aged 50 years plus were more statistically more likely to be prescribed medications (mean= 5.1) compared to the younger adults (mean= 2.3) ($t = -2.3$, $p < 0.01$). These results indicate that you are more likely to be prescribed drugs if you are female, aged over 50 years plus and living in residential accommodation: again these results may not be that surprising as given some of the specific physical and mental conditions associated with the ageing process.

Day activity

Information about the participants' engagement in day activities ranged from attending a blend of day-centre / day opportunities provided by statutory and/or voluntary learning disability services, attending a college of further education, supported employment and/or recreational activities. These services were provided by a range of statutory and voluntary service providers as well as local councils.

The main day activity for many of the adults with a learning disability (approx. 80% per day) was attending a statutory day centre or day opportunity from Monday to Friday, with a mean average of 75% of participants attending this on a full-time basis. For some participants with a learning disability there were periods in the morning or afternoon where they had no structured activities and spend the time within their family home or residential accommodation. No significant differences

were found in the use of statutory and voluntary day activities for the variables of accommodation, age and gender.

Table 4: Primary and hospital healthcare utilization

	Total (N= 97)
GP	94%
Dentist	89%
Optician	73%
Social worker	69%
Podiatry	61%
Practice Nurse	60%
Home help	60%
Physiotherapist	35%
Psychiatrist	35%
Community LD nurse	28%
Speech & Language Therapist	26%
Occupational Therapist	16%
A&E Dept.	13%
Admission to hospital	13%
Challenging Behaviour Team	4%
Psychologist	2%

Primary and hospital healthcare costs

Table 4 illustrates the primary and hospital healthcare utilization for the adults with a learning disability in the last twelve-months. The main health professionals accessed were the GP (94%) followed by the dentist (89%), optician (73%), social worker (69%), podiatrist (61%), practice nurse (60%), home help (60%), physiotherapist (35%), psychiatrist (35%), community learning disability nurse (28%), speech & language therapist (26%), occupational therapist, attending the A&E dept. (13%), admission to hospital (13%), challenging behaviour team (4%) and psychologist

(2%). No significant differences in service utilization were found for these primary and hospital healthcare services compared with where you lived, age and gender.

Table 5: Primary and hospital healthcare costs (N= 92)

Variable	Mean	Standard Error	95% Confidence interval
Age (yrs)	48.70	1.49	45.73 – 51.66
No. of physical conditions	2.98	0.19	2.61 – 3.35
No. of mental conditions	0.75	0.09	0.57 – 0.93
Total cost of primary healthcare	£1,048.71	122.10	£806.17 – £1291.25
Total cost of services delivered in hospital	£1,230.24	361.73	511.70 – 1,948.78
Total drug costs	£411.56	90.08	232.62 – 590.50
Total day activity costs	£21,384.78	944.84	19,507.97 – 23,261.59
Residential care costs	£15,840.43	2,217.51	£11,435.63 - £20,245.24
Total health and social care costs	£39,915.72	2,393.76	£35,160.80 - £44,670.64

Total health and social care costs

Table 5 above provides descriptive statistics for the sample (N= 92) for residential care, cost of day activity, cost of primary healthcare, cost of hospital healthcare, drug costs, and total health and social care costs per annum. The total cost of primary healthcare was approximately £1,048 per annum, total cost for hospital healthcare was £1,230 per annum and total drug costs were £411. The total cost of residential care was £15,840. The total cost of day activity was £21,384. Table 5 illustrates that total health and social care costs were found to be approx. £39,916 per annum: and

were dominated by residential care costs of £15,840 and total cost for day activity of £21,384.

In undertaking the health economic analysis, costs were only available for 92 of the 97 participants: 58 participants with a learning disability lived with their families and 34 participants resided in residential accommodation (supported living scheme (N= 25), residential group home (N= 7) and a nursing home (N= 2)). The mean cost of residential care was £41,715.29 per annum (standard error: £1782.74; 95% confidence interval: £38,088.27 - £45,342.31).

Table 6: Difference of mean costs by group for males and females (N= 92)

Mean of variable	Male (N= 46)	Female (N= 46)	Difference	t-value	p-value
Drug cost	207.75	615.37	407.61	2.31	0.02
Hospital cost	1488.11	972.37	-515.74	-0.71	0.48
Primary Care cost	1,079.82	1,017.60	-62.22	-0.25	0.80
Day Activity	21,623.91	21,145.65	478.26	-0.25	0.80
Residential care	12,992.61	18,688.26	5,695.652	1.29	0.21
Total health and social care costs	37,392.20	42,439.24	5,047.047	1.05	0.29

With respect to bivariate analyses as can be seen in Table 6 above, significant differences were evident in drug costs between males and females. Table 6 shows that males (£207) cost approximately £407 less per year than females (£615) in respect of prescribed medicines. There were no significant differences between males and females in respect of other aspects of care and total health and social care costs. Table 7 below shows that for each additional mental health condition this increases drug costs by £261.

Table 7: Drug costs

Variable	Average marginal effect	Standard error	Z-score	p-value
Age	-6.68	7.45	-0.9	0.37
Male	-544.20	267.15	-2.04	0.042
No. physical conditions	67.40	54.77	1.23	0.218
No. mental conditions	261.01	126.41	2.06	0.039
Residential accommodation	126.73	179.78	0.7	0.481

N = 92

Log pseudolikelihood = -622.74

AIC = 13.67

BIC = -263.27

Marked differences were evident in respect of primary healthcare costs (£1,492 v £789: $p < 0.00$) and total health and social care costs (£64,417 v £25,553: $p < 0.00$) between those who resided in residential accommodation compared to those living with families (see Table 8 see below). Those who resided in a residential accommodation cost slightly under £39,000 more on average per year than those living with their families approximately (see Table 8).

Table 8: Difference of mean costs by group for those living in residential accommodation versus those with family carers (N= 92)

Mean of variable	Residential (N= 34)	Family (N= 58)	Difference	t-value	p-value
Drug cost	421.16	405.93	-15.22	-0.08	0.94
Hospital cost	657.78	1,565.82	908.03	1.21	0.23
Primary Healthcare cost	1,492.44	788.59	-703.86	-2.89	<0.00
Day Activity	20,130.16	22,120.26	1,990.11	1.02	0.31
Residential care	41,715.29	672.41	-41,042.88	-25.34	<0.00
Total health and social care cost	64,416.82	25,553.01	-38,863.82	-13.67	<0.00

In Table 9 below, significant correlations were observed between the number of physical health conditions and hospital healthcare costs, as well as between age and residential accommodation and total health and social care costs. The number of mental health conditions experienced is seen to achieve borderline significance in respect of drug costs. Likewise, age is seen to achieve borderline significance in respect of primary healthcare costs.

Table 9: Pairwise correlations

Variable		
Number of physical conditions	Correlation coeff.	p-value
Drug costs	0.0284	0.79
Hospital costs	0.3346	<0.00
Primary care costs	0.1750	0.10
Day Activity	-0.0248	0.81
Residential	0.10	0.33
All healthcare costs	0.13	0.22
Number of mental conditions		
Drug costs	0.1873	0.07
Hospital costs	-0.0095	0.93
Primary care costs	-0.0712	0.50
Day Activity	-0.0803	0.43
Residential	0.0641	0.53
Total health and social care costs	0.0921	0.38
Age		
Drug costs	0.0359	0.73
Hospital costs	0.0265	0.80
Primary care costs	0.1831	0.08
Day Activity	-0.0124	0.90
Residential	0.4276	<0.00
Total health and social care costs	0.3825	<0.00

Table 10 below shows that at the mean, those who reside in residential accommodation have annual primary healthcare costs approximately £783 higher than those who live with their families, controlling for the other variables shown. Each additional physical condition is associated with an increase in primary healthcare care costs of £146. Each additional mental condition adds £261 to drug costs (see Table 6). With respect to all health and social care costs combined as can be seen in Table 10, only those living in residential accommodation had significantly different costs of the variables examined.

Table 10: Annual health and social care delivered in the community costs

Variable	Average marginal effect (£)	Standard error	Z-score	p-value
Age	-0.70	8.79	-0.08	0.94
Male	38.35	213.18	0.18	0.86
No. physical conditions	146.33	46.52	3.15	<0.00
No. mental conditions	-184.72	108.85	-1.70	0.09
Living in residential accommodation	783.30	293.82	2.67	0.00<

N = 92
Log pseudolikelihood = -723.83

AIC = 15.8720.27
BIC = -314.49

Methods for Phase 4

Aim

Developing a family and community support model for older adults with a learning disability and their ageing family carers: using an evidence-informed decision making model

Design

This study employed a roundtable methodology bringing together a range of stakeholders in order to develop a family and community support model for older adults with learning disabilities and their ageing family carers. The Model for Evidence-Informed Decision-Making in Public Health (The Canadian Institutes of Health Research, 2004) provided the framework for the roundtable discussions and the actionable outcomes that were to stem from these.

In order to facilitate the development of actionable outcomes as a result of the three-day stakeholder events, the Research Steering Group comprising a range of representative stakeholders (from learning disability statutory, voluntary and community sectors; learning disability and ageing academics/researchers; healthcare and public health agency staff, and ageing family carers of older adults with learning disabilities), along with the findings from a recent regional qualitative study (see Hanna-Trainor et al., in preparation: see below), identified four key areas for the stakeholders to explore (see Table 11). These four areas were selected based upon a review of the most up-to-date evidence and policy reviews (Slevin et al., 2011), and that the Research Steering Group members agreed upon would promote the rights of all persons with disabilities to live in their local communities including their family home, prevention of loneliness and community exclusion, and avoid where possible age-related disabilities (UN, 2006; Innes et al., 2012; Taggart et al., 2012; Wark et al., 2014).

Table 11: Four key areas of consensus

- 1) Planning for the older person with a learning disability as they age
- 2) Supporting ageing family carers
- 3) Re-shaping learning disability services and
- 4) Inclusive communities

Participants

In total, over 180 key stakeholders from across Northern Ireland participated in a series of three one-day workshops to explore and agree the way forward for how services for this population are commissioned, developed and delivered for the future. These include personnel from the: learning disability statutory sector (N= 66); learning disability voluntary sector (N= 57); ageing family carers (N= 20); mainstream older persons statutory and voluntary organisations (N= 15); learning disability academics and researchers (N= 9); Department of Health and also Health & Social Care Board (N= 6); Colleges of Further Education (N=6); Public Health Agency (N= 3); Equality Commission (N= 2) and the Client Patient Council (N= 2). The personnel comprised of policy makers, commissioners, senior managers and managers from both the learning disability statutory and voluntary organisations, as well as mainstream older persons statutory and voluntary organisations. Each organization was purposefully selected to ensure a range of participants were represented.

Roundtable Workshops

The morning part of each workshop focused upon knowledge synthesis. Based upon two international experts within this field (Prof Mary McCarron and Prof Philip McCallion), they provided a summary of the most-up-to-date international high quality evidence of the health and policy reviews of older adults with a learning disability and the serious concerns/threats facing their ageing family carers and the need to develop more robust family support models fit for the 21st century. This included a review of the perceptions of older adults with a learning disability pertaining to ageing (Innes, et al., 2012; Burke et al., 2014), transition into older

services (Innes et al., 2012; Wark et al., 2014), and their ageing family carers (Innes et al., 2012; Taggart et al., 2012; Wark et al., 2014).

This was supported by one of the research team (Dr Lisa Hanna-Trainor) providing a summary of the findings of the earlier phases (Phases 1 & 2) of this funded project that explored the needs and preferences of older adults with a learning disability, their ageing family carers and learning disability statutory and voluntary service providers regarding '*ageing, retirement and transitions*' within the context of Northern Ireland (see Hanna-Trainor et al., in preparation). This was followed by a succinct summary of the regional government policies and directives within Northern Ireland regarding older adults with a learning disability, their ageing family carers and learning disability statutory providers (incl. future direction, financial resources, human resources, etc.) ('Equal Lives', DHSSPSNI, 2005; Compton Report, 2011; Learning Disability Service Framework, 2015).

The afternoon part of each workshop focused upon developing actionable outcomes or knowledge products using a roundtable methodology in order to create the environment in which the research evidence can be clarified, interpreted and applied. Each roundtable accommodated groups of between 10 - 12 people; in total there were 16 roundtables held over the three days in February 2016 across Northern Ireland in three different locations to ensure a representation of urban and rural areas. Each roundtable was facilitated by a member of the Research Steering Group (as described above) and supported by one of the participants who attended on the day: this enhanced the rigour of the themes/sub-themes identified within each group. The facilitator provided a succinct summary of the evidence, and provided opportunities for all the participants to explore and discuss the challenges services currently faced in each of the four areas, before facilitating the participants to use the knowledge on producing specific actionable outcomes for that area. The facilitator asked the same four questions (see Table 1 above) at each roundtable to all the stakeholders.

Analysis

Through guided discussion and use of flip charts, the specific themes/sub-themes and wording was agreed upon and recorded on flip charts. These were further shared to all the stakeholders at the end of each day in order to seek further clarity and agreement on the specific actionable outcomes. Field notes were used by several members of the research team to record any disagreements and further clarify all the outcomes.

The roundtables were focused on producing a number of clear actionable outcomes in the form of both practical and policy recommendations that would further the process of knowledge translation in order to develop a family and community support model for older adults with a learning disability and their family carers fit for the 21st century. Four areas were identified and agreed as illustrated in Table 11, and all focused upon knowledge synthesis whereby the most up-to-date evidence, alongside regional research findings and international expert opinions, were shared to empower all the stakeholders to make more evidence-informed decisions and come to a consensus approach.

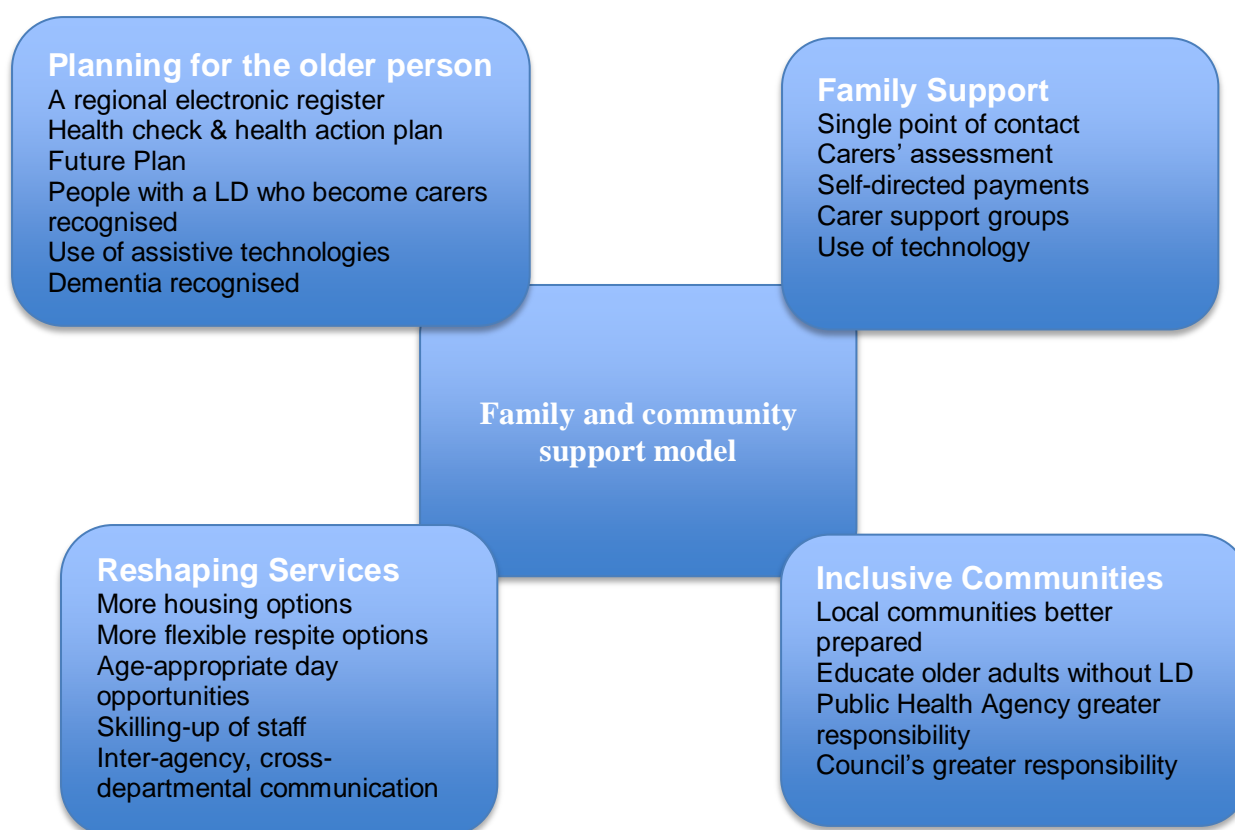
Following the three-day workshops, the Research Steering Group met on a number of occasions to review all the written feedback from the 16 roundtables and to agree on the actionable outcomes. These took the form of both practical and policy recommendations, which would lead to the development of a family and community support model for older adults with a learning disability and their ageing family carers.

Another outcome was to lobby the constituencies responsible for commissioning, financing, developing and delivering services for this population by developing a regional consensus policy document to promote more evidence-based, age-appropriate, efficient and cost-effective service across the statutory, voluntary and community sectors. Therefore, the research steering group also developed a policy brief document that was to be developed for the various government agency departments in Northern Ireland (i.e. Health; Housing; Education; Finance) (see attached accompanying policy brief document).

Findings of Phase 4

The findings will be presented in three sections using participants' excerpts. Section 1 will provide a succinct summary of the participants' shortcomings in existing services within Northern Ireland. Sections 2 and 3 report the practice and policy recommendations that underpin the synchronized and enhanced family and community support model using the four strands identified in Figure 3.

Figure 3: Family and community support model for older adults with a learning disability and their ageing family carers



Theme 1: Planning for the Older Person

Many of the family carers and statutory, voluntary and community sector participants strongly highlighted that there was little understanding of the concept of 'ageing', 'retirement' and 'transition' as many older people with a learning disability had no alternative age-appropriate opportunities to opt into other than what was currently being provided. Most of the participants across the roundtables also reported that many people with a learning disability also did not recognize the concept of

'retirement'; 'from what to what' as learning disability services did not discuss or plan for this event. The provision of current learning disability services also provided the opportunities for the person with a learning disability to congregate and importantly *'meet their friends'*. Furthermore, for the family carers they emotionally reported that current learning disability statutory and voluntary services provided them with the *'daily respite'* and a *'life-line'* they so often needed to preserve their caring role.

Many of the ageing family carers reported that they did not have a future plan in place whenever they are unable to care, yet it was the *'most single worrying part of life'*. *'A lack of future planning'* whenever there was a change in family circumstances due to a death or critical illness of a main carer was recognised by all across the roundtables, with many participants reporting this lack of planning leading to *'crisis management'*. Participants from statutory learning disability services recognised the need for developing a future plan, but reported being *'unprepared'*. Some learning disability statutory and voluntary sector participants reported that there were some adults with a learning disability also providing care for an ageing parent but this *'dependent relationship'* was not always recognised by statutory services.

There was agreement across all the stakeholders that there was no regional and local database to identify older people with a learning disability and their ageing family carers in order to proactively plan for the transition into older years.

Theme 2: Family Support

There was a strong consensus across the stakeholders that there was *'a lack of support for how the person with a learning disability ages in place with their ageing family carers'*. Many of the family carers and voluntary and community sector participants stated that these ageing family carers had *'no single point of contact'* for practical information and emotional support. Few family carers had had a carer's assessment and only small numbers of families were availing of direct payments/self-directed support. Many of the family carers testified they had *'little to no opportunities to meet with other family carers'*. There was some discussion among the participants about the use and benefits of technology across several of the roundtables, however there was a clear agreement of *'a lack of use of*

technology and home adaptations’ to support these ageing family carers to continue to care for an older relative with a learning disability within their family home.

Theme 3: Inclusive Communities

The topic of inclusive communities raised an animated debate among the statutory, voluntary and community participants as well as family carers. It was strongly agreed across many of the roundtables that local communities were *‘largely unaware’ and ‘unprepared’* to engage with adults with a learning disability and their family carers. Community services rarely make the necessary *‘reasonable adjustments’* to enable a person with a learning disability to engage with their communities (i.e. Councils, leisure centres, community groups, Public Health Agency).

Theme 4: Current Service Provision

A strong theme that has already been highlighted but has been repeatedly emphasized across the three days was *‘the lack of age appropriate planning/service provision for alternative day opportunities for older people with learning disabilities’*. This included *‘a lack of appropriate and flexible respite options’* for older adults with a learning disability and their ageing family carers. All the family carers and voluntary and community sector participants also stressed the *‘shortage of suitable residential/supported living provision’*. Many of the statutory and voluntary sector participants voiced concern about the *‘lack of training for all staff on the health needs of older people with a learning disability and the needs of their ageing family carers’*. There was some discussion among the learning disability statutory and mainstream ageing service providers about the *‘lack of communication and collaboration between both services’* and how *‘they continue to work in silos’*.

Many of the participants from the learning disability statutory services indicated that *‘current policies and practices of their organisations often do not adequately support staff to engage in age appropriate evidence-based practices’*. Overall, this lack of understanding of ageing and retirement has led to a lack of planning for adults with a learning disability as they transition into older years.

Practical Outcomes / Recommendations

A consensus approach was also sought from all the participants to clearly identify a number of practical recommendations.

Theme 1: Planning for the Older Person / Life Care Plan

It was agreed that *‘a regional electronic register/database should be developed’* to help identify the needs of all adults with a learning disability and their family carers. All adults with a learning disability should have *‘a health check’*; their needs should be identified early, and appropriate prevention measures put in place to assist healthy ageing. Future Planning needs to happen early; include an emergency plan; considering siblings (family approach); and establish a circle of support for older people with a learning disability and their ageing family carers. The needs of adults with a learning disability who develop dementia need to be addressed with each country’s regional dementia strategy. Many of the participants recognised that some adults with a learning disability who become the *‘main carer’* for an adult parent and that these individuals need to be recognized and supported.

Theme 2: Family Support

All the family carers and learning disability statutory and voluntary participants strongly reported that there needs to be *‘one point of contact where families can access practical information and signposting about all service/support opportunities’* within their area/community. It was stressed that many of the family carers’ assessment also needs to include the needs of the family unit: *‘a family carer’s assessment’*. It was recognised that families should be better encouraged and supported to use self-directed payments to ensure that their family member with a learning disability continues to have a *‘meaningful day’* and that they have *‘access’* to the support they need to remain within the family home. It was unanimously agreed by all participants that more *‘carer support groups’* providing family carers with *‘practical information’, ‘emotional support’, ‘signposting’, ‘empowerment’ and the ‘opportunity to engage with other family carers’* were needed across all regions of Northern Ireland. Many of the participants highlighted a greater use of technology could be employed to address the health needs of the person with a learning disability; to support family carers to maintain caring within their own home; and support the needs of the family carer (i.e. tele-health, home adaptations).

Theme 3: Inclusive Communities

There was some discussion about the role of local communications and a number of participants from all of the groups reported that *'local communities need to be better prepared'* to understand and support the needs of older people with disabilities and their carers. A number of participants particularly from the learning disability voluntary and mainstream ageing voluntary services indicated that it would be beneficial to educate older adults without learning disabilities, to mentor and support adults with learning disabilities to access and engage in mainstream community older people's services (i.e. Volunteering, Men Utd, Men's Sheds, Gardening Clubs, Photography Groups, University of the Third Age): thereby enabling them to engage in their local communities.

The role of the Public Health Agency was discussed, and it was agreed that in order to ensure a healthy learning disability population and healthy carers, the Public Health Agency had a responsibility to make the necessary *'reasonable adjustments'*¹ to all their community programmes to ensure that they *'are accessible to this population'* (i.e. healthy living, health promotion, health education, vaccinations, health issues (men's health, women's health, mental health)). Likewise, local Councils were also identified by many of the participants to have a *'responsibility'* to ensure that all community programmes operating within their localities made the necessary *'reasonable adjustments'* for this population, (i.e. learning and education, employment support, sports, leisure and recreation, the arts, travel and access to transportation, home safety, benefits, planning your retirement).

Theme 4: Reshaping Services

Discussions were intensified when the topic of examining current learning disability service provision (i.e. residential provision, building based day-centres, respite/short breaks, community programmes) was raised among the learning disability statutory service personnel and the other stakeholders. Despite some debate, agreement was obtained that statutory, voluntary and other housing providers *'needed to develop*

¹ Under section 49a of Disability Discrimination Act 1995 (as amended by the disability discrimination (Northern Ireland) Order 2006), public authorities when carrying out their functions must have due regard to the need to 1. Promote positive attitudes towards disabled people. 2. Encourage participation by disabled people in public life.

more age-appropriate...bespoke housing options for older adults with a learning disability' (i.e. respite/short breaks, residential, supported living opportunities, nursing options) by linking with different voluntary organisations, housing providers and relevant care providers. Similarly, many of the participants reported that all services needed to develop *'more flexible respite options'* (i.e. *'adult family placements, overnight respite, short breaks, etc.'*).

Many participants recognised the availability and number of building-based day-centres in their local area for this population, as they provided *'opportunities for people with learning disability to meet their friends'* and *'give structure to their day'* but also, they offered *'daily respite for many ageing family carers'*. However, there was agreement among many of the participants that these building based day-centres needed *'adapted'* and *'a more age-appropriate day opportunity provision was required'* to ensure that these facilities have the capacity to continue to meet the needs of an older person with a learning disability; by ensuring that *'availability and flexibility of the service is afforded to all'*.

To reshape such services, many of the participants across the various stakeholder groups reported the *'skilling-up of staff that work within learning disability statutory services'* and also *'mainstream ageing service providers'* to improve their *'knowledge'* and *'skills'* of the changing demographic and the health needs of older people with a learning disability and their ageing family carers.

It was agreed that greater inter-agency, cross-departmental communication was required to facilitate the sharing of information (*'changing demographic and the health needs of older people with a learning disability and their ageing family carers'*, *'sharing best practice'*, *'resources'*, *'budgets'*) and *'people held accountable'*. Policy makers, commissioners and senior managers need to *'rethink on how services are commissioned'* for older people with a learning disability and their ageing family carers, to ensure that *'all service users have access to a service that meets their needs'* and ensures their *'continued inclusion within their own communities'*.

Policy Outcomes / Recommendations

A consensus approach was also sought from all the participants to clearly identify a number of policy recommendations that would translate the practical recommendations above into achievable and deliverable outcomes.

There was a consensus across many of the stakeholder groups to establish a *'Family Manifesto/Charter'* to protect the rights of both the older person with a learning disability and their ageing family carers, overseeing and guiding on issues such as a Carer's Bill Direct Payments and Entitlement Legislation (Make the Call Campaign, COPNI, 2015). Likewise, all the family carers and many of the learning disability and mainstream older person services from the statutory and voluntary sectors highlighted the need to develop a *'Carers Bill'* aimed at promoting the rights and requirements of all family carers.

Many of the statutory, voluntary and community sector participants, as well as family carers, stressed the development of *'a regional cross-departmental working group'* to oversee the establishment and operational management of an *'Expert Committee'* to advise on how services can be developed to meet the needs of ageing family carers and older people with a learning disability given the practice recommendations listed above. This committee should have the authority to hold organisations (i.e. HSCTs, Councils, Public Health Agency) and the Trust's Carers Champions accountable. All family carers and people with a learning disability should be supported to *'access the Equality Commission'* and the *'Law Centre'* if their needs are not being met.

It was strongly recommended that all service providers (learning disability and mainstream older person services statutory and voluntary organisations) need to evidence *'leadership'* and *'share responsibility to build the relationships'* required to ensure that *'existing service models are reshaped and co-designed'* with people with a learning disability to create new cost-effective solutions. New solutions (*'best practice'*) must be proactive and require a *'change of mind-set'* on the behalf of all stakeholders, to enable older people with a learning disability to become actively involved within their local communities (*'positive risk-taking'*). Everyone has a responsibility to ensure that our communities are welcoming and inclusive of all and

that older people with a learning disability are provided with opportunities to have their contribution valued and have a real role within their individual communities. These recommendations should be the '*outcomes under which leadership are held accountable*'.

Discussion

Introduction

In the discussion, we demonstrate how we have answered the first research question in that the family and community support model is a prerequisite to *‘ensure an effective transition from adult services to ones geared to meet the needs of older persons with a learning disability living with their ageing family carers?’* We have also answered the second research question: *‘What are the costs associated with different options?’* Furthermore, we provide a succinct summary of the key findings for the reader in order to demonstrate how then we have met the specific aims and objectives of this study.

We provide an integrated discussion of our findings, supported by the most up-to-date evidence regionally, nationally and internationally, and highlighting regional directives/policies, to inform the family and community support model. We conclude by proposing a series of practice and policy recommendations that if fully translated into practice will develop more age-appropriate, evidence-based, efficient and cost-effective systems that thereby will achieve a successful transition for these adults with a learning disability and their family carers into their older years (Equal Lives, DHSSPSNI, 2005; Learning Disability Services Framework, DHSSPSNI, 2015; RQIA's, 2016; Health & Wellbeing: Delivering Together, DHSSPSNI, 2016).

Ageing, retirement and transitions

This section relates to the first aim that examined how ageing, retirement and transitions are best managed for older adults with a learning disability. There were two objectives:

- 1) To examine what people with a learning disability would like to do in their *‘old age’* and the family carers' aspirations for their relative with a learning disability
- 2) To explore what currently constitutes age-appropriate residential, day activity, respite/short breaks and community programmes within the learning disability and mainstream older persons services

In Phases 1 and 2 we found of this regional research project incorporating 87 adults with a learning disability, 34 family carers, 60 statutory service providers and 16 senior managers via focus groups and 1-1 interviews, a limited understanding of the concepts of *'ageing'*, *'retirement'* and *'transitions'*.

Ageing

In Phase 1 we found that *'ageing'* was viewed by many adults with a learning disability as negative (i.e. *'illness'*, *'dementia'*, *'no longer having choice'*, *'loss of friends'*), and only a handful of service users regarded getting older as a positive experience (*'opportunity to do something different'*, *'have more freedom'*). There was no clear agreed age across all stakeholders when an adult with a learning disability was identified as *'older'* and therefore the process of *'retirement'* was not explored by the service user, carers and service providers: from what to what (*'a no exit strategy existed'*).

The findings of this study differ from the themes identified by Buys et al. (2008) in their qualitative study of 16 older adults with a learning disability in Australia that explored their perceptions of active ageing. They found that these older adults wanted to *'be empowered, be active, and have a sense of security, maintain skills and learning, have congenial living arrangements, have optimal health and fitness, be safe and feel safe, and have satisfying relationships and support'*. One explanation for this difference is that the older adults within our sample had received little education on *'ageing, retirement and transition'* and therefore found the questions difficult to answer.

Cordes & Howard (2005) in another qualitative study in Australia found that of 60 adults with a learning disability, many had insight into what they would like to do with regards employment and leisure activities: this was based upon the individual's existing histories/experiences of these concepts. However, when questioned about getting older and retiring, many of these participants had also a poor concept of ageing and retirement and had engaged in no retirement planning. Most also had little understanding of volunteering. The authors concluded that adults with a learning disability should be educated about what ageing is and engage in planning early for your retirement: transitioning into the next stage of your life.

In a qualitative study that explored how day-care staff promoted active ageing among older adults with a learning disability in Australia, Buys et al. (2012) found that staff strongly focused on encouraging active ageing. However, individual characteristics, circumstances and experiences of the adult with a learning disability needs to be considered when planning transitioning from day services, employment or voluntary work to reduced activity. Buys and colleagues argued that day-care staff *'have a vital role to play in encouraging and facilitating active ageing, as well as informing strategies that need to be implemented to ensure appropriate care for this diverse group as they proceed to old age'* (p. 1113).

Retirement and transitions

In Phases 1 and 2 this study has undoubtedly shown that *'ageing'*, *'retirement'* and *'transitions'* are not clearly defined and therefore not proactively planned for by statutory service providers: findings further validated in Phase 4. All the participants agreed that *'retirement'* for older adults with a learning disability was a *'meaningless term.'* The older adults with a learning disability and their ageing family carers have had to fit into existing traditional service models of day-care buildings, residential provision and short breaks/respite: these services were not be-spoke to the ageing needs of this population. There are examples of alternative arranges such as day-opportunities, supported accommodation and family placements but these were far and few and again do not address the specific ageing needs of older adults with a learning disability and their ageing family carers.

The question must be asked as to what are adults with a learning disability *'transitioning into'* when they become *'older'*? Staff did recognise that *'transition planning was needed'* but also reported they were restricted by the lack of available options. There were limited, if any, age-appropriate alternatives offered in terms of day provision, preparation for retirement and recreation/activity, and also short breaks/respite, that were bespoke for older adults with a learning disability and their ageing family carers. There was little or no co-ordination of statutory learning disability and older persons programme of care: both services continued to work in silos. Likewise, there were few opportunities for older adults with a learning disability to engage within their non-disabled peers in their local communities.

Therefore, it can be purported that people with a learning disability are still regarded as an homogenous population despite the state-of-the-art evidence, the regional, national and international policies, and recent human right principles that emphasise how the demographic and health needs of this population and their ageing family carers needs to be taken into account when planning and delivering services (UN, 2006; Equal Lives, 2005; Learning Disability Service Framework, 2012; DHSSPSNI, 2014, 2016; RQIA Report, 2016).

Service utilization and future costs

This section relates to the second aim of the study that examined the most effective service models (residential, day-care/opportunities and community programmes) for older people with a learning disability and their ageing family carers. There were two objectives:

- 3) To document the current use of day services and family support services by older persons with learning disabilities and their family carers, and their anticipated future need for services, including the transition arrangements in place
- 4) To examine the costs of residential, day activity, respite and domiciliary care within the learning disability and older persons' programme of care and project likely future costs

Using structured 1-1 interviews and the Client Service Receipt Inventory, we were able to clearly document the health and social care service utilization and costs with a sample of 97 adults with a learning disability living in residential accommodation or those residing with their families across Northern Ireland.

In Phase 3 we found that the mean cost of residential care was £41,715.29 per annum and the total cost of day activity per annum was £21,384. The total cost of primary healthcare was approximately £1,048 per annum, total cost for hospital healthcare was £1,230 per annum and total drug costs per annum were £411. Significant differences were evident in drug costs between males (£207) and females (£615): males cost approximately £407 less per year than females. Each additional

physical health condition was associated with an increase in primary healthcare care costs of £146. For each additional mental health condition this increased drug costs by £261.

Our figure of £41,715.29 per person per annum (N= 92) was very similar compared to the Strydom et al. 2010 figure of £41,080 per person per annum for a sample of 210 older adults with a learning disability aged 60 years plus in London. Strydom and colleagues found that residential costs constituted the largest proportion of this health and social spend as we also found in this Northern Irish study: although our costs for health and social care and residential costs combined, were higher at £64,416 per annum compared to the English study of £51,220 per annum. One explanation for this disparity is that the Strydom study was conducted about eight years ago and service costs will have changed since then. Another explanation may have been how services have been costed. However, caution must be taken from these figures as this may not be a representative sample of adults with a learning disability. We did not achieve the second part of objective 4, pertaining to projecting the likely future costs of services for older adults with a learning disability given a number of practical and methodological challenges we encountered.

Nevertheless, those older adults with a learning disability who resided in residential accommodation in Northern Ireland cost approx. £39,000 more per year than those living with their families. Northern Ireland has a lower number of adults in residential care compared to Ireland and Great Britain (McConkey et al., 2006; DHSSPSNI, 2014; RQIA, 2016). Yet we have a steadily increasing ageing population who continue to reside in the family home with parent/sibling carers together, supported by a traditional learning disability model that we have argued is not meeting the needs of both these cohorts as the current community models/services are sparse, ad hoc and not based upon the needs of this ageing population, but are service and financially driven. This has been supported by the recent RQIA (2016) undertaken in Northern Ireland.

Strydom and colleagues reported that despite these older adults with a learning disability accounting for only 0.15%-0.25% of the population, they however consume up to 5% of the total care budget. The authors highlight that any interventions that

meet the needs of adults with a learning disability and their family carers, and is cost-effective, should be sought. These characteristics should therefore be taken into consideration when planning and delivering the synchronized and enhanced family and community support model we propose in this report.

Estimating population size and predicting costs

The World Report on Disability (WHO, 2011) calls for '*progress in . . . disability cost estimates and better data*' (p. 42). Ouellette-Kuntz et al. (2016) in Canada examining national prevalence administrative data sets reported the difficulties in projecting learning disability prevalence rates as these are '*highly dependent on reliable prevalence, mortality statistics and accurate age-structure data for the population*' (p. 254). Likewise, the recent RQIA Report (2016) in Northern Ireland highlighted the difficulties in obtaining accurate prevalence rates of learning disability regionally, as this information is not collated in a single regional common information system with agreed data sets. Therefore, it would be difficult to predict accurately future costs.

If such regional data was collated in Northern Ireland and was accurate, then, we could improve our projections of our learning disability prevalence rates. Likewise, if we were to undertake a larger cohort study of the costs of services, then we could more accurately predict future costs of learning disability services stratified by accommodation, level of disability, physical and health conditions, age and gender. At best, what we can offer now is a crude estimate.

Nevertheless, the evidence is that Northern Ireland like the rest of the world has a significantly increasing ageing learning disability population, with chronic co-morbidity physical and mental health conditions that increase costs of health and social care as clearly highlighted in Phase 3. The DSPSSNI (2014) have already highlighted the dramatic difference in prevalence rates among those young people with a learning disability aged 0 – 19ys (49.4%) compared to the 20 – 44yrs (21.7%), 35-49yrs (14.9%) and 50yrs plus (13.6%) groups (see Table 1). This is in addition to a growing number of children with a severe/profound learning disability with very complex health needs. Commissioners, policy planners and service providers need to acknowledge the future health and social care needs and costs associated with this growing ageing population: not planning ahead is no longer an option.

Predicting costs in Northern Ireland

In 2015-2016, according to the RQIA Report (2016) the HSC Board investment in the learning disability programme of care was £265.2 million, which was 7.79% of the total investment in health and social care in that year for Northern Ireland (£3.406 million). This proportion has remained around this level since 2005-2006 (range 7.21% - 7.79%). This investment covers services to children as well as adults. But how much of this budget is planned for older adults with a learning disability? In the Netherlands, learning disability ranked first in disease-specific costs for the 0 – 64 year age group, accounting for 9% of healthcare expenditure (Polder et al., 2002).

It can therefore be argued that there has been a lack of investment in the learning disability programme within Northern Ireland over the last ten years. This under investment, given the current financial and austere times, may continue for another 10 - 20 years thereby the needs of this double cohort ageing population will remain unmet again despite the clear regional, national and international evidence that ‘*a one size model does not fit all*’. Reports within Northern Ireland clearly illustrate that the health and social care needs of older adults with a learning disability, and their ageing family carers, have not been met (McConkey et al., 2006; Taggart et al., 2012; DSPSSNI, 2014; RQIA, 2016). Although we were unable to predict future costs for this population due to practical and methodological reasons, and the lack of a single regional common information system with agreed data sets to give accurate prevalence rates, we can strongly argue that greater investment is required for this proposed family and community support model (see Figure 3).

Practical Recommendation

One of the practical recommendations of this study is to develop a regional electronic register/database in line with UNCRPD, Article 31, to help identify the numbers and needs of all people with a learning disability and their family carers in Northern Ireland. This would predict the likely rise in numbers over the coming 10-20 years, as well as the potential for measuring community participation, health inequalities, access to services and morbidity levels.

Effective service models

This section relates to the third aim that examined the most effective service models family and community (i.e. residential, day-care/opportunities and community programmes) supports for older persons with a learning disability and their family carers. There was one objective:

- 3) To reach a consensus across stakeholders as to what is considered to be optimal transitional arrangements and ‘best’ practice in service provision for older persons with learning disabilities living with family carers.

Using a roundtable methodology, we were able to bring together over 180 stakeholders in order to develop a family and community support model for older adults with a learning disability and their ageing family carers. The Model for Evidence-Informed Decision-Making in Public Health (The Canadian Institutes of Health Research, 2004) provided the framework for the roundtable discussions and the actionable practical and policy outcomes that were to stem from these. Using a consensus approach, we have synchronized and enhanced a family and community support model for older adults with a learning disability and their ageing family carers based upon four core areas:

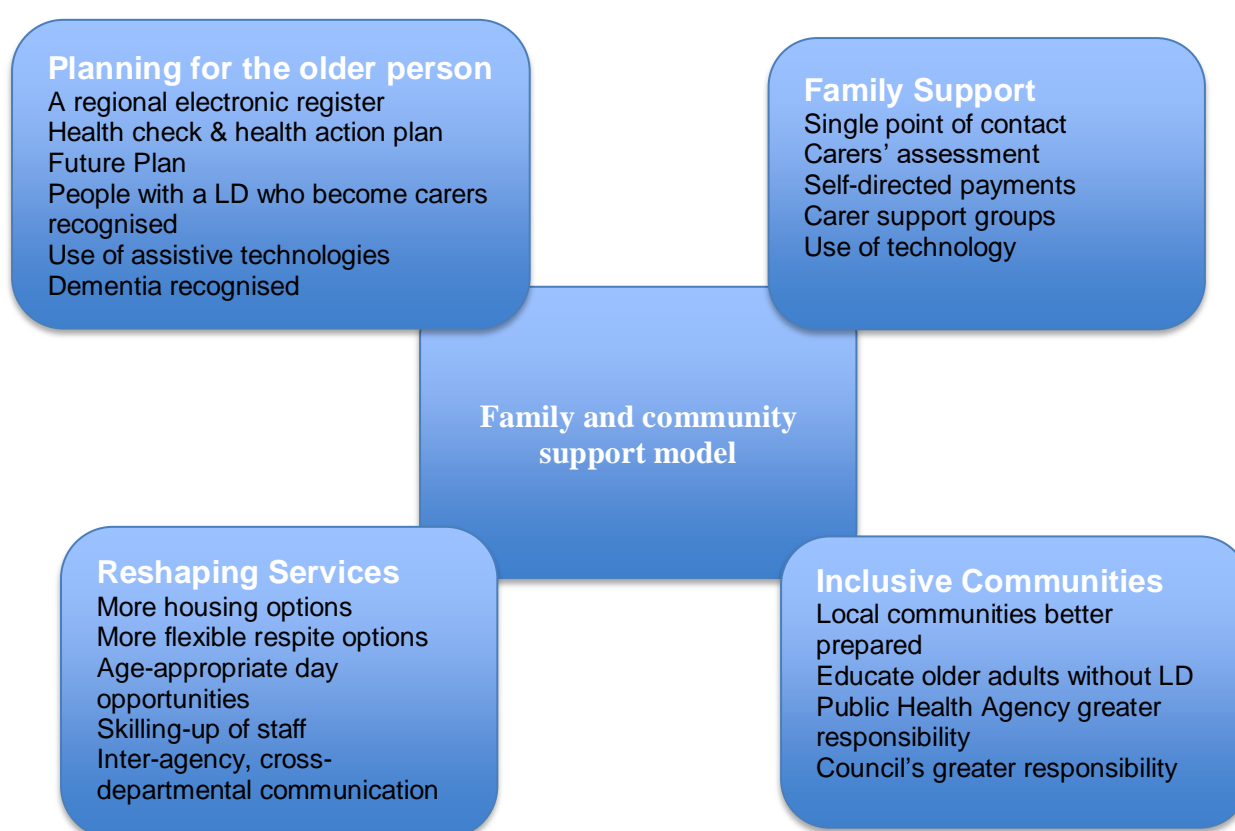
- Planning for the older person;
- Family support;
- Reshaping services and
- Inclusive communities (see Figure 3 below).

Family support model

In many westernised countries today, many people with a learning disability live with their families. The results of this study and similar studies in Northern Ireland have also shown that living with families is not only the preferred option for most children and adults with a learning disability but also for their parent/sibling carers (Taggart et al., 2012; RQIA Report, 2016). Barnes et al. (2010) reported that research has now moved away from looking at family dysfunction and increasingly recognizes the successful, resourceful ways in which families adapt and provide care. Furthermore,

this study has shown like other national and international studies that the family support model that exists worldwide is a more cost-effective model compared to the provision of residential accommodation/supported living schemes (Hatton & Emerson, 1996; Emerson, 2005; Stancliffe & Lakin, 2005; Strydom et al., 2010). We must use the lived experience, the knowledge and the expertise of these adults with a learning disability and their family carers in identifying family-centred customised solutions.

Figure 3: Family and community support model for older adults with a learning disability and their ageing family carers



Therefore, it is important that we explore the different age-appropriate options that can be developed to support these families to continue caring. Some options already exist but are offered on an ad hoc basis and there is an inequity of these schemes across Trusts in Northern Ireland (RQIA Report, 2016). These include family support groups, use of direct payments, and use of family placement schemes, supporting siblings to become future carers and engaging with the voluntary sector to support families as they age. We must also acknowledge that the care provided by the parent / sibling can break down either due to health or death of the main carer, or

challenging behaviours/mental health in the person with a learning disability, and to avoid a crisis situation emergency and future plans need to be developed (Taggart et al., 2012; Ryan et al., 2013). These now will be explored considering the findings of this study.

Support groups

In Phase 1 and 4 this study found that the family carers frequently reported they did not have a single point of contact for practical/emotional information and a lack of support groups. There are a range of bespoke family support groups offered to ageing family carers in the UK, Australia, Canada and the USA focusing on providing information, and offering emotional and instrumental support to families in order to build upon their existing strengths. These groups empower families within their own social context as a form of prevention, maintenance and also crisis management. According to Seltzer & Gidden (2011) there are a number of benefits of these family support groups:

- 1) Enhancing a sense of community
- 2) Mobilising resources and supports
- 3) Sharing responsibility and collaboration
- 4) Protecting family integrity
- 5) Strengthening family functioning and
- 6) Adopting proactive programme practices.

Family support groups provide a range of services including education and training, counselling, information on future planning, advice on statutory learning disability services and mainstream community provision, mailing lists of other ageing family carers, how to obtain home modifications, guardianship, and legal and financial planning (Janicki et al., 2003). These specialist centres have also been funded and developed through government funds and private and charitable grants targeted at serving older family caregivers of adults with a learning disability. These centres are designed as co-ordinated, ‘one-stop’ informational centres for family carers.

Practical Recommendation

One recommendation from this study is that each Trust develops and funds an appropriately resourced family carer support group providing family carers and siblings with practical information, emotional support, signposting on statutory/voluntary learning disability and older peoples' services, empowerment and the opportunity to engage with other family carers (i.e. face to face groups, online format, message board and lists of resources). Likewise, sibling support groups should also be developed to prepare them to become future carers.

A second recommendation is that parent carers (including siblings) should have access to education and training programmes, designed to provide support and optimise their ability to provide care for the older person with a learning disability. This should include counselling, information on future planning, promoting better health and managing of stress. Family support programmes should be individualised, multi-faceted, focused on early intervention and delivered over multiple sessions.

Self-directed support or direct payments

This study found that there was minimal use of self-directed support or direct payments by these ageing family carers across Northern Ireland. The Direct Payment Scheme was introduced to allow family carers to define, choose and direct their own supports giving them increased control over the services most suitable for their son/daughter with a learning disability and also the family's requirement. The money allocated can be utilised to pay for personal/support assistants, domiciliary care, day-care, transport, supported employment, home modification, respite care and therapies. There is growing evidence to illustrate the success of the direct payment scheme for older family carers in the UK and USA (Stainton, 2002, Stainton & Boyce, 2004, Heller & Caldwell, 2005, Caldwell & Heller, 2007, Caldwell, 2008). However, few family carers in this study reported using direct payments.

Ageing family carers have reported the scheme to be very positive; giving them increased choice and empowerment, increased flexibility in scheduling services and a greater sense of trust of the personal assistants. In addition, these ageing family carers also indicated greater feelings of confidence and optimism, and decreased

their anxieties about going out for social activities and out to work. The older people with a learning disability also experienced greater community integration and leisure satisfaction.

Practical Recommendation

A recommendation of this study is that older people with a learning disability living in the community should be offered a range of meaningful day opportunities/activities that includes tailored support to promote independence in activities of daily living: direct payments is one method to facilitate this.

Short-term breaks/respite

Many of the family carers in Phases 1, 3 and 4 of this study reported the ad hoc and sometimes inappropriate arrangements of short-term breaks/respite (i.e. in congregated residential accommodation) across Northern Ireland: this has been confirmed by the recent RQIA Report (2016). Despite the strength of family carers to continue caring, some require alternative care or respite breaks for a short period of time (Kersten et al., 2001). In comparison to statutory learning disability residential provision for short-breaks/respite, individualised alternative family support models have been developed in the form of '*family placements*' across the UK. This involves adults who volunteer, being recruited and trained and offering to provide care for a young person, adult and more recently an older person with a learning disability in their own home for a short-break/respite (i.e. a few hours per day, overnight, a weekend or longer).

McConkey & McConaghie (2004) reviewed a family placement scheme in Northern Ireland that targeted older adults with a learning disability. Using 1-1 interviews barriers to identifying such placements included: identification and recruitment of volunteers (most had a background in learning disability), training, police checks and low payment. Nevertheless, all volunteers expressed their satisfaction and joy in offering a respite placement within their family home for an older person with a learning disability. The main benefit for the ageing family carers was the chance of a break but they also valued the relationship they had built with the volunteer. The

older adult with a learning disability reported that they had greater opportunities to participate in a range of activities while on placements.

Practical Recommendation

A recommendation of this study is to develop more family placement schemes across Northern Ireland, with statutory learning disability services working in partnership with the different range of voluntary organisations, to develop these schemes for older adults with a learning disability.

Reciprocal caring

Some learning disability statutory and voluntary sector participants at the roundtables in Phase 4 reported that there were a small number of adults with a learning disability also providing care for an ageing parent but this '*dependent relationship*' was not always recognised by statutory services. Both the older adult with a learning disability and their ageing family caregivers face increasing challenges and many continually worry about the future when the family caregiver is unable to provide care (Walker and Walker 1998; Bowey & McGlaughlin, 2004; Black & McKendrick, 2010; Taggart et al., 2012). The problem is perpetuated by a situation whereby all too often, mutually caring older families slip through the net statutory learning disability services and older persons programme of care, and primary healthcare services (Foundation for People with a Learning Disability, 2010). These services are generally unaware of the issues associated with mutual caring, often because of professional boundaries and the blurring of lines of responsibility. Consequently, some families can fall between all three services and continue to provide mutual care with little to no support.

Practical Recommendation

A recommendation of this study is that statutory services should recognise early those adults with a learning disability who become carers for their ageing parents, recognising their needs and supporting them and offering short breaks / respite in the same way as it is made available to other family carers.

Future planning

During the roundtable discussions in Phase 4 many of the ageing family carers reported that they did not have a future plan in place whenever they are unable to care, yet it was the '*most single worrying part of life*'. Participants from statutory learning disability services also recognised the need for developing a future plan, but reported being '*unprepared*'. '*Succession or future planning*' is based upon ageing family carers proactively planning if they become unable to continue to care for their son/daughter with a learning disability within their own home. Magrill (2005) reported that ageing family carers wanted to develop an emergency plan and a future planning if professional staff dealt with the issues around such decisions sensitively and carefully. Taggart et al. (2012) in Northern Ireland found that many ageing family carers aspired to develop a future plan but few carers actually had developed a definitive plan with siblings and a legal representative.

Through a Public Health Agency Knowledge Exchange Scheme Award, Taggart and colleagues in 2013-2014 developed and delivered to a training manual and a two-day training programme for all statutory and voluntary staff across Northern Ireland (Taggart & Thompson, 2015). The future planning programme was based upon six core themes: exploring your own future plan; circles of support; person centred planning and emergency plans; signposting housing and support options; making sound financial and legal decisions; direct payments; and supporting a family carer to make a future plan. This was rolled out across Northern Ireland and over 200 staff attended the two-day training programme. However, Taggart & Thompson (2015) reported that only a few staff fully engaged with families to begin developing a future plan, citing organisational difficulties (i.e. future planning not identified as a priority, competing workload issues, not given sufficient time to work with families, etc.).

Practical Recommendation

A recommendation of this study is that all parents of adults with a learning disability develop a future plan, including an emergency plan; taking into account the contribution of siblings (a family-centred approach); and establishing a circle of support for older people with a learning disability and their ageing family carers. The training resource already exists.

Engaging with the voluntary sector to support families

It was clear from the emotive words of the family carers in Phases 1 and 4, that current statutory learning disability day care provision was not flexible regarding evening and weekend activities; although many carers applauded the provision of the day-centres during the week to give them that daily respite and compassion of the staff. Nonetheless, having a personalised day care package that entailed evenings, weekends and having flexibility would greatly enhance their quality of life as a carer and provide a more relevant service for their family members with a learning disability. Findings that have been echoed in other countries but also here in Northern Ireland where provision is patchy (McConkey et al., 2004; Black & McKendrick, 2010; RQIA, 2016).

Within Northern Ireland, there are no bespoke community-based services that have specifically targeted the needs of ageing family carers of people with a learning disability. A regional charity, Positive Futures, was successful in obtaining a grant from the Big Lottery to develop the 'Better Futures Project'; this was a 4-year Project (2012-16). This project focused on developing and delivering a range of support options designed to meet the needs of ageing family carers of people with a learning disability. In total the 'Better Futures Project' provided direct support and interventions to 81 family units composed of 115 family carers (aged 60-94yrs) who cared for 88 dependent adults with disabilities (203 people in total).

Through a two-phase evaluation (Taggart, 2016), the aims and objectives of the 'Better Futures Project' were not only achieved but clearly exceeded expected outcomes. The 'Better Futures Project' developed a bespoke array of family services (i.e. respite/short breaks, support groups, practical information, emotional support, knowledge, information sharing, signposting, emergency and future plans) that have clearly met the specific needs of each of these families caring for a relative with a learning disability. Narratives from the family carers, Positive Futures and Trust staff all highlight the achievements and '*lifeline*' this project has offered these ageing carers to continue to support and care for their relatives with a learning disability within their family homes.

Positive Futures have successfully developed a family centred model operating in one area of Northern Ireland. The project model has focused on a number of evidence-based elements in its design. It has responded to the current needs of the ageing family carer and person with a learning disability, thus allowing more capacity for thinking about and looking to the future. It has enabled these ageing family carers to continue to care for their relatives with a learning disability within their own homes for as long as possible.

Comparative costs with other similar services are not easy to find. One approach is to examine comparable services using the unit costs for 2014 produced by the PSSRU. For example, one hour of social worker, client-related work in adult disability services on average costs £67. The cost of a family support worker with direct client contact is £50 per hour and social work assistant costs are £29 per hour. More pertinently, if the older family carers were no longer able to support his/her relative with a learning disability within the family home, based on current figures, the HSC Trusts would have to pay approx. £41,000 per year for a residential placement (Strydom et al., 2010; PSSRU, 2014). Individuals requiring specialist care can cost in excess of £150,000 per annum (PSSRU, 2014). It can be argued that the 'Better Futures Project' offers a low-cost support package to each family that can provide opportunities to support these families without large increases in overall spend.

Practical Recommendation

It is a recommendation of this study that each Trust work in partnership with a voluntary organisation to deliver this family model. The potential of extending this bespoke family model to all family carers of adult persons with a learning disability will foster the resilience of families and their capacity to provide effective informal support for their relatives throughout adulthood.

Community supports

The results of this study illustrate that it was strongly emphasized by many of the participants in all of the phases of this study that there was a '*shortage of suitable residential/supported living provision*', a '*lack of age appropriate planning/service provision for alternative day opportunities*' and '*a lack of appropriate and flexible*

respite options’ for older adults with a learning disability. We will now look at residential, day-care/day opportunities and community programmes and how reshaping these can be a more age-appropriate, efficient and cost-effective model for meeting the needs of older adults with a learning disability and their ageing family carers.

Residential provision

Despite the preferred option for many older adults with a learning disability and their family carers to remain within their family home, just less than a fifth of adults with a learning disability in Northern Ireland resided in some form of community residential accommodation or supported living scheme or nursing home. The recent RQIA Report (2016) found that there is a marked differential in the proportion of people in residential accommodation and supported living schemes across Northern Ireland depending on where you live (i.e. Trust).

Findings from this study also indicate that the current residential provision offered to the family carers was not geared to the ageing needs of the older adults with a learning disability. It is important when developing residential facilities/supported living schemes that attention to design, strategic location and resident selection are considered. It is also important that strategic partnerships with voluntary learning disability providers and aged care facilities are developed to deliver alternative residential options.

Practical Recommendation

A recommendation from this study is to develop more housing options beyond traditional statutory learning disability residential and nursing options, such as supported living, home ownership, co-ownership and shared lives (as highlighted above) options, by linking with relevant social care providers and, where relevant, different housing providers.

Day centres/opportunities

This study has shown that in all the Phases of this study, that for the majority of older adults with a learning disability attending a statutory day centre was a vital life line:

both for the service user in order to meet friends but also as important for the family carer to give them the daily respite they so often needed to support them to continue caring. We found few, if any, older adults with a learning disability in our study attending an older person's day-centre.

Holland (2000) reported that day-care environments need to be responsive to the changing demographic, and health and social lifestyles of ageing and acknowledge retirement when appropriate. With the focus on person centred planning, supported living, individual budgets and direct payments (Equal Lives, DHSSPSNI, 2005; Valuing People, 2009; Learning Disability Services Framework, DHSSPSNI, 2013), older adults with a learning disability and front-line staff need to be aware of the opportunities that these may present to enjoy a different pattern of living and activities as they retire from traditional day services, thereby opening up a new range of opportunities for social and leisure pursuits, but they also need to have opportunities to maintain their friendships with other people with a learning disability.

There is some debate that learning disability day-centres may prevent older people with a learning disability from retiring, as programmes often have no upper age limit. On the other hand, they may play important roles in supporting such transitions. Bigby (2004), for example, found that when she interviewed older people with a learning disability in Australia that they valued continued active engagement with their local communities, expressed a desire to continue learning, still wanted to participate in more leisure activities and placed a high value on structured activities. However, many older people with a learning disability are reliant upon ageing family carers and/or paid carers to present opportunities and provide support to exercise and support them in participating in activities. Day-centres have the capacity to better meet such needs.

Few studies have examined older people with a learning disability using mainstream older people day-centres. Bigby & Balandin (2005) examined the extent to which programmes available to the non-learning disability aged community were accessible to older people with a learning disability in Australia: 40 day and leisure centres were identified. A small number of older people with a learning disability accessed more than half of these services and overall there was a willingness to include this group

in generic services. The findings indicate that the issues for older people with a learning disability differ little from those of other minority groups. The authors proposed that learning disability services have a role in brokering services for their older learning-disabled clients and continued planning and collaboration between learning disability and older person services can benefit all older people.

A keystone of the transformation of services for people with a learning disability is that individuals themselves are facilitated in identifying the outcomes that are meaningful to them and that services have the organizational structure to respond positively to these self-identified needs (Becker et al., 2000).

Practical Recommendation

A recommendation of this study is that learning disability day-centres engage with older person day-centres in order to scope the enablers and barriers to such integration. This would be in keeping with the DHSSPSNI (2005) paper on '*Ageing in an Inclusive Society*' that endorsed delivering integrated services that would improve the health and quality of life of older people with a learning disability, and have access to services and facilities that meet their needs and priorities.

Another recommendation of this study is to review existing statutory learning disability day opportunity provision to ensure that it is fit for purpose and meets the changing needs and choices of older people with a learning disability.

Community involvement in planning retirement options

There is a greater recognition of the impact of ageing today, with many countries now taking an inclusive approach to active ageing in the non-disabled population (WHO, 2002). However, this inclusive approach to active ageing has not been targeted at the disabled population because learning disability services have traditionally provided a cradle to the grave service, without proactively focusing on the promotion of healthy and active ageing (Heller et al., 2014).

Similarly, this study has shown that few older adults with a learning disability engage in mainstream older person community programmes such as leisure/recreation

activities, community retirement groups, volunteer programmes, etc. The findings of this study highlight that the needs of adults with a learning disability were largely *'misunderstood'* and that those in the community providing public services did not always make the *'reasonable adjustments'* necessary to allow an adult with a learning disability to be inclusively involved within their activities/services: *'offering places in a leisure centre is not enough, who is going to support that person with a learning disability to access that service, we (staff) can't do everything. Staffing will not allow it'*. There was agreement that more education and awareness of learning disability and the support needs of someone with a learning disability would help build knowledge and allow those with disabilities to engage better with their local communities (Dodd, 2008; Buys et al., 2012).

As people with a learning disability age, they may also disengage from specialist services and fail to develop new avenues for social-connectedness and community participation, so risking further isolation (McCarron et al., 2013). In keeping with the principles of the UN (2006), older adults with a learning disability should be afforded the opportunity to retire from the day-to-day activity that they have been attending all their lives, whilst being helped to maintain inclusive relationships within their communities.

In addition, older adults with a learning disability are at increased risk of isolation, loneliness and depression due in part to their reduced involvement in their local community (Bigby et al., 2011; McCarron et al., 2013). A link between social disconnectedness as well as poorer health and wellbeing has been shown among non-disabled ageing adults (Cornell & Waite, 2009) and although this may be worse for those with a learning disability, both learning disability and older person services have not targeted how adults with a learning disability transition into community projects and the potential benefits of this. This is even though the participation of people with a learning disability in their communities is widely encouraged in policy (Equal Lives, DHSSPSNI, 2005; UN, 2006; Learning Disability Services Framework, DHSSPSNI, 2013; RQIA's, 2016; Health & Wellbeing: Delivering Together, DHSSPSNI, 2016).

Practical Recommendation

It is a recommendation of this study that older adults without a learning disability are recruited to mentor and support people with a learning disability to access and engage in mainstream community older people's activities (e.g. Volunteering, Men Utd, Men's Sheds, Gardening Clubs, Photography Groups, University of the Third Age).

Another recommendation of this study is to promote the health and well-being of older people with a learning disability and their ageing family carers via the Public Health Agency, which has a responsibility to reach out and support people to access these services, by making the necessary 'reasonable adjustments'² to all their mainstream community health programmes to ensure that they are accessible to this population (i.e. healthy living, health promotion, health education, vaccinations, health issues (men's health, women's health, mental health)).

Local Councils also have a responsibility to reach out to support people to ensure that all mainstream community health programmes operate within their localities by making the necessary 'reasonable adjustments' for this population, (i.e. learning and education, employment support, sports, leisure and recreation, the arts, travel and access to transportation, home safety, benefits, planning your retirement and well-being).

Research shows that older adults with a learning disability want to remain active and to contribute to their local communities, but services need to provide them with the appropriate opportunities to do so. Stancliffe et al. (2015) reported on the acceptability of an innovative 'Transition to Retirement' (TTR) programme that supported older adults with a learning disability (aged 45 years plus) to transition into retirement and engage in their local communities. Wilson et al. (2013) reported that the non-disabled mentors, if trained and supported, were willing to support an adult with a learning disability to join their mainstream older community group. The TTR

² Under section 49a of Disability Discrimination Act 1995 (as amended by the disability discrimination (Northern Ireland) Order 2006), public authorities when carrying out their functions must have due regard to the need to 1. Promote positive attitudes towards disabled people. 2. Encourage participation by disabled people in public life.

program has been shown to be a viable low-cost option for developing a retirement lifestyle for older adults with a learning disability supported by trained mentors in Australia (Stancliffe et al. 2015). Northern Ireland could replicate this model.

Training

This study has shown that adults with a learning disability have poorer physical (i.e. sensory problems, chronic constipation, epilepsy, reflux / swallowing difficulties, digestive problems, arthritis, hypertension, diabetes, circulatory problems, respiratory problems, asthma, cardiovascular problems, osteoporosis and cancers and mental health (i.e. depression, anxiety, dementia and schizophrenia). Older females residing within a residential accommodation/supported living scheme were more likely to have poorer health compared to their male counterparts. These results reflect similar studies nationally (McCarron et al., 2015) and internationally (Haveman et al., 2011; Heller et al., 2016). It is therefore important that all staff in both learning disability and mainstream older persons programme of care receive training on the health needs of this population in order to support a smoother transition into the ageing process.

Bowers (2012) has developed an online training manual for residential staff to support adults with a learning disability who are ageing. The contents include: normal changes as a person ages, building successful partnerships, decision making (advocating for individual involvement), end of life care, understanding, communicating and managing common systems and accessing resources.

Dodd (2008) reported that education about the ageing process and expected changes *'are a fundamental right of people with a learning disability, and will enable them to identify physical and mental health symptoms earlier, understand changes, and be less reliant on the observations of others'*. Dodd argues that educating older people with a learning disability to change aspects of their lifestyle and health behaviours is an important strategy, and can support them to be more involved and informed in developing their retirement plans. However, day-care personnel first need to be educated, and then they can educate and support these adults with a learning disability to understand the ageing process, retirement and transitions.

Practical Recommendation

A recommendation of this study is to offer training to all staff within both learning disability services and the older persons programme of care, and across the voluntary and community sector to improve their attitudes, knowledge and skills development to focus on the health needs of older people with a learning disability and their ageing family carers.

Interagency working

Unlike the other parts of the UK, Ireland and many westernized countries, Northern Ireland is in a unique position as it has a joint health and social care system. This is clearly supported by a number of policy drivers that focus on ageing in learning disability (Equal Lives, DHSSPSNI, 2005; Learning Disability Services Framework, DHSSPSNI, 2013; RQIA's, 2016; Health & Wellbeing: Delivering Together, DHSSPSNI, 2016). However, statutory learning disability services and mainstream older persons programme of care are fragmented into sectors by funding mechanisms (day-care, residential provision, health, etc.). This has clearly been evident from the findings of this study in all phases that reported '*a lack of communication and collaboration between both services*' and how '*they continue to work in silos*'. Similar findings have also been reported in USA, Australia, Canada, UK and Ireland (Bigby, 2010).

Despite such policies, there remains a lack of decision-making protocols at service system interfaces. However, ambiguity exists in terms of where should costs and responsibilities lie in terms of developing services for older adults with a learning disability (i.e. clearer definitions, access based on age, retirement planning, transitions, etc.). Wark et al. (2014) explored the major factors that staff experience in supporting older adults with a learning disability in rural Australia. They found that '*funding, training and access to services*' were three main impediments. They stated:

'That both services and government funding bodies have the ability to plan to overcome both current and future problem areas. This identification of impediments may facilitate individuals to receive more appropriate assistance,

which in turn may lead to improved quality of life and maintenance in the community rather than premature admission to the congregate-care system.'

This leaves the question how can these two-service systems interface with each other. A cross-departmental working group should be put in place to oversee the establishment and operational management of an '*Expert Committee*' to advise on how services can be developed to meet the needs of ageing family carers and older people with a learning disability given the practical recommendations listed above. New solutions ('*best practice*') must be proactive and require a change of mind-set on the behalf of all stakeholders, to enable older people with a learning disability to become actively involved within their communities ('*positive risk-taking*').

Policy Recommendations: Translating research into practice

This study has provided a number of practical recommendations interwoven throughout the discussion as identified in the shaded boxes above. For these recommendations to be fully translated into practice, a series of policy recommendations have also been developed: these recommendations were also developed in Phase 4 during the consensus workshops with the stakeholders. These recommendations are based upon the four components of the family and community support model for older adults with a learning disability and their ageing family carers as proposed in Figure 3.

We acknowledge the organisational, cultural, leadership, attitudinal and financial obstacles in translating evidence into practice, therefore in order to fully operationalise these recommendations this report concludes by providing a series of policy recommendations that clearly address these barriers. This is clearly evidenced in the words of one staff member '*resources are fantastic if we get them, but actually if the attitudinal barriers are broken down, our lives would be so much easier in terms of facilitating... people with a learning disability are bottom of the pile and it doesn't matter how many strap lines or how many policies you have*'.

Change is more than attitudinal: systems and processes are needed to be modified. The findings of this study highlighted that change was unsettling for the adults with a learning disability (i.e. '*loss of routine, loss of friends*') and their ageing family carers

(i.e. *'turmoil, upheaval'*) in relation to *'ageing, retirement and transitions'*. Although the front-line staff within the focus groups in Phase 1 of this study recognised changes need to occur, conversely, they reported on their *'lack of freedom'* to influence change within their organisation as this was *'beyond their control'*. Learning disability service managers also recognised the challenges associated with changing the status quo and the implications this would have for policy and practice in Phase 2: *'traditionally learning disability services have been provided from birth to death and that is the traditional line of thought...it would require quite a significant change in the whole commissioning process through local collaboration to change that'*. This was further echoed by a number of the statutory senior learning disability stakeholders in Phase 4 across the different roundtables that *'current policies and practices of their organisations often do not adequately support staff to engage in age appropriate evidence-based practices'*.

The Canadian Institute of Health Research (2004) defined knowledge translation as:

'The exchange, synthesis and ethically-sound application of knowledge, within a complex system of interactions among researchers and users, to accelerate the capture of the benefits of research through improved health, more effective services and a strengthened healthcare system.'

Translating research into practice or knowledge translation as it has been more frequently called, is understood as a dynamic process characterized by engagement of stakeholders/partners in various ways at different points in the process from knowledge creation to action (Graham et al., 2006): as evidence throughout the four phases of this study. Internationally, there is a greater recognition of the use of best available research to inform evidence-based practice across medicine, health and more recently public health. The Model for Evidence-Informed Decision-Making in Public Health offers three important benefits: 1) adoption of the most effective and cost-efficient interventions; 2) prudent use of scarce resources; and 3) better health outcomes for individuals and communities (see Figure 4).

Figure 4: Model for Evidence-Informed Decision Making in Public Health



However, knowledge translation in the field of learning disability has received limited focus and attention (Kuntz et al. 2006; Martin et al. 2010) with even less in the area of ageing in learning disability. The family and community support model highlighted in Figure 3, offers an innovative approach for services to support these ageing families to continue to care for their relative with a learning disability within the family home. This proposed family and community support model clearly recognizes the importance of self-determination amongst older adults with a learning disability and their ageing family carers, and greater community inclusion (Equal Lives, DHSSPSNI, 2005; UN, 2006; Learning Disability Services Framework, DHSSPSNI, 2013; RQIA's, 2016; Health & Wellbeing: Delivering Together, DHSSPSNI, 2016).

The recommendations from this study, which has included regional engagement and support from statutory, voluntary and community sectors, clearly identify both the practical and policy directions for how commissioners, policy makers and service providers should plan and develop specific services for older people with a learning disability and their ageing family carers in the future. These practical and policy recommendations should act as the catalyst for the Dept. of Health, Health Board, Public Health Agency, Local Councils and Trusts to plan and develop services fit for the 21st century. In any future planning, cross reference should be made to Community Planning Processes in terms of service development and implementation (see

http://www.ruralcommunitynetwork.org/DataEditorUploads/Strategic%20Framework%20for%20Community%20Development%20for%20NI%20_Final%20Draft%20Version-Sept%202011_.pdf).

Policy Recommendations

Establish of **Family Manifesto/Charter** to protect the rights of both older people with a learning disability and their ageing family carers, overseeing and guiding on issues such as a Carer's Bill; Direct Payments; Entitlement Legislation (Make the Call Campaign, COPNI, 2015).

To develop a **Carers Bill for Northern Ireland** aimed at promoting the rights and requirements of family carers.

A cross-departmental working group should be put in place to oversee the establishment and operational management of an '**Expert Committee**' to advise on how services can be developed to meet the needs of ageing family carers and older people with a learning disability given the recommendations listed above. This committee should have the authority to hold these organisations (i.e. HSCTs, Councils, Public Health Agency) and the Trust's Carers Champions accountable.

All family carers and people with a learning disability should be supported to access the **Equality Commission** and the **Law Centre** if their needs are not being met. All service providers (statutory and voluntary) need to evidence **leadership** and share responsibility to build the **relationships** required to ensure that existing service models are reshaped and co-designed with people with a learning disability to create new cost-effective solutions.

New solutions ('best practice') must be proactive and require a **change of mind-set** on the behalf of all stakeholders, to enable older people with a learning disability to become actively involved within their communities ('positive risk-taking').

Everyone has a **responsibility** to ensure that our communities are welcoming and inclusive of all and that older people with a learning disability are provided with opportunities to have their contribution valued and have a real role within their individual communities.

The recommendations from this policy brief should be the outcomes under which **leadership are held accountable**.

Strengths and limitations of study

This was a large regional study involving representation from all stakeholders including public patient involvement from both the adults with a learning disability and their ageing family carers, as well as from stakeholders.

Phases 1 and 2 employed a qualitative methodology using focus groups and 1-1 interviews. Like all qualitative studies, it is open to the criticism of size and generalisability. A strong aim of this study was its representativeness across all five Trusts, therefore allowing saturation to be reached and confirmed by the research team: 87 adults with a learning disability, 34 family carers and 60 statutory service providers. Application of Newell and Burnard's (2006) content analysis methodology successfully facilitated the identification of the themes, sub-themes and concepts. The question remains though, can the findings of a regional study be transferred for consideration to the wider world of learning disability. The researchers conclude that while the specific geographical location needs to be acknowledged, the robust design of the study and sense of 'fit' between the findings and those of previous studies gives credence to the results. The themes and sub-themes that were identified were then further revalidated in Phase 4 during the discussions at the roundtable workshops with over 180 stakeholders.

In Phase 3, it was originally planned to collate this data by undertaking a postal survey although as we developed the data collection tool and in consultation with the Research Steering Group, it was agreed this data would be best collected involving a face-to-face 1-1 structured interviews. Likewise, the original plan was to recruit 300 participants to provide a representative sample of adults with a learning disability and stratify this sample by the different levels of mild, moderate and severe/profound learning disability thereby providing us with a more comprehensive overview of the health and social care service use and costs. However, we encountered significant problems with identification and recruitment despite offering a monetary incentive. Despite numerous attempts in advertising this phase of the study via both statutory and voluntary learning disability services and the contacts already established in Phases 1 and 2, we were only able to recruit 97 participants. We acknowledge this is a shortcoming of this phase and the results presented should be interpreted with caution.

A further limitation is our reliance on ageing family carers and paid carer reports for detailed information concerning level of learning disability, physical and mental health conditions, challenging behaviour, service engagement, etc. rather than undertaking a detailed assessment of the persons' health and clinical records. Nevertheless, the rates of physical and mental illness in our study were found to be like those in earlier research studies examining the same population such as that by Cooper et al. (2010) and Strydom et al. (2010).

Although we made a detailed assessment of costs and service use, it is possible that some elements relevant to overall costs were not as accurate as we would have liked; for example, we used average costs in residential care settings not the actual individual cost of care. Likewise, given the broad range of voluntary day opportunities that this sample was availing of, we used the average costs and not the actual individual cost of these activities: as they were not always available to us.

Phase 4 focused upon a roundtable methodology in order to seek a consensus approach for a community support model. We have attempted to be all-inclusive in purposely inviting a representative sample of stakeholders from learning disability statutory, voluntary and community sectors; learning disability and ageing academics/researchers; healthcare and public health agency staff, and ageing family carers of older adults with a learning disability. The limitations of this phase of the study correspond to criticisms of other qualitative approaches (Parahoo, 2014), in that the participants may be those highly motivated to participate. However, this was an innovative approach to obtain a consensus approach across a broad range of stakeholders. A number of checks were undertaken to ensure the practical and policy recommendations identified by the participants were accurate, truthful and creditable (Slevin & Sines, 2000). It was beyond the scope of this phase to consult with older adults with a learning disability as we had already engaged with them in a series of focus groups in Phase 1, and have already obtained their views of their aspirations of '*ageing*', '*retirement*' and '*transitions*'.

Impact of Personal and Public Involvement

Conducting focus groups with older adults with a learning disability and their ageing family carers greatly improved the outcomes of the study as it gave these participants the opportunity to contribute to the research and have their voices heard. Likewise, interviewing senior management across the five HSCTs from both learning disability services and mainstream older persons programme of care gave us a unique insight into the workings of these care directorates and afforded management the opportunity to have a say in how service provision should be managed in the future.

By having ageing family carers present in the Research Steering Group, Phase 1, 2, 3 and 4 ensured that policymakers and those from statutory and voluntary and community sectors, heard directly from their service users and their family carers. The policy and practical recommendations put forward from the consensus workshops have the potential (if implemented) to impact the following areas;

- 1) Impact the direction of future policy
- 2) Potential influence on commissioning of services in the future
- 3) Redesign of statutory, voluntary and community sectors to incorporate greater collaboration and
- 4) More inclusive communities.

Dissemination strategy

It is anticipated there will be a formal launch of the findings of this study, including the practical and policy recommendations in 2017, hosted by the Public Health Agency Research & Development Division. At this event, we then can launch our policy brief document and also post this document to all stakeholders, so they can lobby the various government agency departments in Northern Ireland to influence change (i.e. Health; Housing; Education; Finance) (see attached accompanying policy brief document).

From this main report, there will be three peer-reviewed papers completed for publication:

- Hanna-Trainor et al. (in preparation): A comparison of the views of adults with intellectual disabilities, family carers and professional staff on Ageing, Retirement and Transitions. *Journal of Applied Research in Intellectual Disabilities*.
- Taggart et al. (in preparation): A comparison of the health and social care service use and costs for adults with intellectual disabilities in the UK. *British Journal of Psychiatry*.
- Taggart et al. (in preparation): Development of a family and community support model for older adults with intellectual disabilities and their family carers: *Journal of Policy & Practice in Intellectual Disability*.

This report and papers when published will be shared with the Expert Advisory Panel on Adult Care and Support, Dept. of Health Northern Ireland in 2017. The Dept. of Health in Northern Ireland is currently working to develop proposals for change to adult care and support for consultation in April 2017, in accordance with the commitment made in the Health Minister's ten-year vision *Health and Wellbeing 2026: Delivering Together* (DSPSSNI, 2016).

In addition, this report will be shared with the National Institute for Clinical Excellence (NICE) 'Care and Support of Older People with a Learning Disability Review (2015-1018: <https://www.nice.org.uk/guidance/indevelopment/gid-swave0776>). The Dept. of Health in England has asked NICE to produce a guideline on the care and support of older people with a learning disability. The guideline will be targeted at providers of social care, healthcare providers, social care and housing providers.

Conclusion

This study has examined in detail what is meant by the concepts '*ageing, retirement and transitions*' from the perspective of the older adults with a learning disability, their ageing family carers, and from statutory learning disability and mainstream older person services in Phases 1 and 2. Using structured face-to-face interviews in Phase 3, a cost analysis was undertaken of the health and social care of a sample of adults with a learning disability living in either residential accommodation or their family home. The last phase of this study brought together over 180 stakeholders in order to share the findings of this study and to develop a more age-appropriate, evidence-based, efficient and cost-effective model for these older adults with a learning disability and ageing family carers.

The results of this study, supported by the international literature and regional policies/directives, have led to this synchronized and enhanced family and community support model being proposed. This model is based upon four recurrent themes that have been identified across all four phases of this study (i.e. planning for the older person, supporting family carers, reshaping services and inclusive communities); and these have clearly informed the practical and policy recommendations that have been put forward from by this project in the policy briefing document.

The components of the family part of the model include: having a single point of contact, developing local support groups, ensuring more carers use of direct payments, greater use of family placement schemes, supporting siblings to become future carers, use of assistive technologies and engaging with the voluntary sector to support families as they age. Components of the community part of the model include: more inter-agency collaboration from both statutory and voluntary organisations to develop cost-effective and age appropriate alternatives to traditional services, training front-line to understand the needs of this population and their ageing carers, supporting adults with a learning disability to plan for their retirement, having alternative retirement options, age appropriate day-centres/opportunities, having a range of residential provision, respite/short breaks and involvement in local community programmes. This proposed family and community support model clearly

recognizes the importance of self-determination amongst older adults with a learning disability and their ageing family carers, and greater community inclusion.

If this family and community support model is translated into practice, this model could be attractive to policy makers, service commissioners, learning disability services, mainstream older person services and community groups as this can clearly offer a low cost sustainable intervention. Using existing mainstream community social infra-structures, rather than funding new retirement groups for this population, therefore makes sense when promoting a human rights empowerment and social inclusion agenda and in this manner, improves health and well-being of the service user. This report adds new knowledge by utilizing the Model for Evidence-Informed Decision-Making in Public Health that will allow policy makers, commissioners and service providers to translate research into practice in order to develop a family and community support model to support ageing family carers and older adults with a learning disability. This model could also be related to other neuro-developmental disability groups and adults with chronic mental health problems living in the community.

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